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Table of Contents

Forum: 2009 Pacific Rim Conference, Disability Studies Strand

Forum Editor Introduction

Megan A. Conway & Norma Jean Stodden, University of Hawai‘i at Mānoa, USA

Research Articles

Disabled Literature—Disabled Individuals in American Literature: Reflecting Culture(s)

Miles Beauchamp, Wendy V. Chung, Alliant International University, California, USA

Alijandra Mogilner, Faucon International, California, USA

A Way Forward: Presenting a Post Modern Framework for Disability

Rachel Carling-Jenkins, Monash University, Australia

Holier than Thou: Stigma and the Kokuas of the Kalaupapa Settlement

Akira Oakaokalani Ruddle-Miyamoto, University of Hawai‘i, Mānoa, USA

Ron Amundson, University of Hawai‘i, Hilo, USA

Family Bookmaking: An Approach to Support Parent-Child Language Interactions in Natural Environments

Lisa K. Boyce, Mark S. Innocenti, Lori A. Roggman, Cora Price, Vonda K. Jump, Gina Cook, & Eduardo Ortiz, Utah State University, USA

Book and Media Reviews

Wild Things: Sounds of the Disabled Underground Vol 1

Reviewed by Kevin Dierks

Negotiating the Special Education Maze: A Guide for Parents & Teachers, 4th Ed.

Reviewed by Michael Bailey

Disability Studies Dissertation Abstracts

RDS Information

RDS Subscription Form

Forum: 2009 Pacific Rim Conference, Disability Studies Strand

Forum Editor Introduction

Megan A. Conway, Ph.D. & Norma Jean Stodden, Ph.D.
University of Hawai'i at Mānoa

Aloha! We are pleased to present a forum comprised of four of the papers presented at the 2nd Disability Studies Strand of the Annual *Pacific Rim Conference on Disability* held in May, 2009, in Honolulu, Hawai'i. This year's conference will be held April 12-13 and we are excited to see the Disability Studies Strand grow and develop with every year.

The articles presented in this forum are a wonderful mix of perspectives and cultures, representing a sample of the diversity that is Disability Studies today. In *Disabled Literature: Disabled Individuals in American Literature*, Miles Beauchamp and Wendy Chung provide insight into the vast topic of the portrayal of disability in both modern literature and literature from the past. Rachel Carling Jenkins traveled from Australia to present *A Way Forward: Presenting a Post-Modern Framework for Disability* that explores the history of disabled people in Australia and the current struggle to shift perspectives about disability in that country. Akira Ruddle-Miyamoto and Ron Amundson provide a fascinating look at the link between treatment of Native Hawaiians and the settlement of persons with Hansen's Disease on the Moloka'i settlement of Kalaupapa in *Holier Than Thou: Stigma and the Kokuas of the Kalaupapa Settlement*. Finally, Lisa Boyce et al discuss innovative approaches to supporting children with disabilities and their families in their article *Family Bookmaking: An Approach to Support Parent-Child Language Interactions in Natural Environments*.

We hope you enjoy this forum and we also hope to see you at this year's or future conferences in lovely Honolulu!

Forum

Disabled Literature—Disabled Individuals in American Literature: Reflecting Culture(s)

Miles Beauchamp, Ph.D. & Wendy V. Chung, Ph.D.

Alliant International University, California, USA

Alijandra Mogilner, Ph.D.

Faucon International, California, USA

Portions of this paper were previously presented at the 2009 Pacific Rim Conference on Disabilities, Honolulu, Hawaii.

Abstract: In American literature, disabled characters are often portrayed as “that other” and used to generate fear, pathos, and hatred. This affects how variously-abled individuals are perceived and accepted by society. While writers are being more inclusive and broadening their inventory of characters, many characters are simply a negative plot tool.

Key Words: literature, superstition, evil, stereotypes, disabled, culture

Introduction

The manner in which disabled individuals have been portrayed in modern and contemporary American literature has, for the most part, shown disabled women and men, girls and boys as feared, reviled, misunderstood, or pitied. Disabled characters have been used primarily, if not only, to elicit pathos, fear, or hatred, with the disability eliciting the feeling as much as the character.

Literature affects, not just reflects, society and its views of disabled individuals; so how were disabled characters portrayed, what did they say, do, or become? What was reality-based and what was simple plot-driven necessity? During the later part of the 20th century and certainly into the 21st, especially with the passage of the Americans with Disabilities Act, through the efforts of the Head Injury Foundation and other people with disabled rights-centered organizations, how disabled people are seen has been changing.

The dominant feelings held by nondisabled persons toward disabled persons are so very often sympathy, fear, or distaste; these reactions are often accompanied by avoidance or patronization. These terms also describe how disabled people are treated in American literature—that is, the subject of disability is avoided or the individuals are generally presented in a stereotypical, and often negative, manner. Disabled people are portrayed as helpless, super-abled (pure and good), or evil monsters. While these portrayals may seem unimportant—after all, literature isn’t “real life”—research has shown time and again that portrayals are extraordinarily important and influence culture(s) for decades and beyond.

Disabled Literature

The attitudes towards disabled individuals are as diverse as people are diverse. Some of those attitudes, however, can be grouped together: attitudes of fear, attitudes of revulsion, and

attitudes of pity are just three of the more horrific ones. These attitudes have not only been displayed by people, they have also been imposed upon people—often disabled people. Historically, these attitudes resulted in practices of exclusion and confinement and defined whole people as wholly ill. Sterilization, especially of people with cognitive disabilities, was common in the United States and Europe at one time. Segregation denied people a wider voice, and their experiences, thoughts, and insights were ignored (Pirofski, n.d.).

In the contemporary United States, mainstreaming in schools, physical access to public sites, and technology have all improved access. Access, in turn, made people with disabilities visible and allowed more participation in society and in decision making. Those publicly seeking rights for disabled individuals have been active since the 1940s and have become particularly effective since the 1960s. As a result, in the last half of the 20th century and the beginning of the 21st, there has been movement toward an acknowledgement of the normalcy of disability. Our literature (contemporary United States in this case) is starting to reflect that movement, albeit slowly and sometimes grudgingly. The literature of the nation is making its way from the two-dimensional portrayals of disabled individuals as monstrous, evil, inhuman, or cloyingly pitiful to characters that are fully functional. Those changes in characterization have grown out of a new sociopolitical consciousness about disability, particularly among disabled people themselves, and then from their push to not be characterized as the “other” by everyone else. Reading about the normal-disabled has joined the mainstreamed school and workplace in making America more inclusive (see Pirofski, n.d.).

Self-Awareness

There is another aspect to the appearance of disabled people in literature: to allow nondisabled people to deal with their own fears and become more aware of their own prejudices. Murphy explains:

“The kind of culture the handicapped American must face is just as much a part of the environs of his disability as his wheelchair. It hardly needs saying that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish however little most individuals may embody them. Most handicapped people, myself included, sense that others resent them for this reason: we are the subverters of an American ideal, we become ugly and repulsive to the able-bodied. We represent a fearsome possibility” (1995, p. 143).

Among other things, reading about disabled people reveals to us disquieting truths about our response to traditionally stigmatized segments of the population, making clear that, beneath the benign tolerance that the more “enlightened” among us profess to feel, primal terrors beset us even as they do the least “enlightened.” Reading novels, poems, and plays will not, let us be clear, exorcise those terrors, but by raising the issues to the level of full consciousness, these works can deliver us from hypocrisy and make us aware of how little is altered by mere verbal changes: that superficial re-labeling of which we tend to be so foolishly proud (Murphy, 1995).

Literature as a Mirror of Culture

Literature tells us who we are as a culture; it mirrors our beliefs or challenges them; it helps sell a life-style. Literature has been used deliberately to normalize groups of individuals and create social change. For example, one of the effects of *Uncle Tom's Cabin* (Stowe, 1998) was to make people aware of the negative issues in slavery. *The Bone Collector* (Deaver, 1997) was written not only as a thriller mystery, but also a statement against mercy killing. In *To Kill a Mockingbird*, Harper Lee (1960) masterfully used this fear and distrust of those who are different, in this case the developmentally disabled, to communicate the ignorance this attitude embodies. She uses narrow-minded townspeople to connect with what may be the reader's own narrow views of developmentally disabled individuals. The character, Boo, is presented as dangerous by seeing him only from the townspeople's parochial viewpoint. In the end he is revealed as both compassionate and brave. Literature reflects our realities and our dreams. It tells us what is good and bad and what does not fit into the cultural ideal.

Portraits of Evil

Until recently, the primary societal attitude was that disabled people were less-than-human, evil, or even monsters. During the Victorian period, teratology—the study of abnormalities of physiological development—was represented in cabinets of human curiosities. These displays often included deformed skulls or bones of those who had been disabled in life, and unusual items of clothing for those who had been born as conjoined twins. These displays were eventually commercialized in the form of sideshows popular in the late 19th and early 20th century (Bogdan, 1988). In England, Canada, and the United States, the so-called “freak show” was also a popular entertainment in the first half of the 20th century. People with all sorts of bodily differences such as missing or additional limbs, obesity, hirsuteness, smallness, or tallness were exposed to paying audiences, who gawked at what were often billed as “mistakes of nature.” Thus the disabled (or the just-different) marked the boundaries of humanity and crossed them at the same time. It is this ambiguous state that both fascinated and frightened the audience (Bogdan, 1988).

This cultural background was reflected across literature from children's stories to adult novels and plays until very recently.¹ Any impairment usually made a character into a villain or a monster. Traditional children's tales often feature Cyclops, giants, evil one-armed captains, and those who can be identified as evil simply because they are physically very different from the beautiful “good” people (Goldman, 1990).

Probably because people understand most easily that which is most obvious, or has physical form, physical characteristics have always been used to set evil people apart from good people (Reese, 1998). For example, it is easy to see that Captain Hook is evil—he has the talk and most definitely the walk. The hook hand makes him even more menacing. The reason for the use of image to convey an idea goes back to the basic developmental patterns of childhood. Children's language development begins with nouns—the concrete objects which they can see, touch and easily understand (Reese, 1998). Thus, people understand the clues that concrete objects provide to enhance their understanding of ideas and situations. So clues have been found or created: dwarfism came of evil parents; mental illness is still often believed to be the result of possession by the devil or demons.

During the mid-1980s, children's literature began to change (Goldman, 1990). In response to activist groups, and due to some of these groups' own in-house publishing efforts, a body of literature has grown up that spans from picture books to young adult novels. However, it should be noted that quantity is not the same as quality. Goldman (1990) noted that the number of books for children and youth that depicted disabled characters increased after 1975, but most of the books offered bland depictions of disability, outcomes were predictable, the characters were one dimensional, and the content was often more like a sermon than a story.

The idea that different is evil was true in adult literature as well as literature for children: Captain Hook was replaced by Captain Ahab. Not so long ago, missing limbs, twisted bodies and chronic illnesses were all attributed to witchcraft in both children's and adult literature (Ellison, 2006). When evil was marked, or made visible, it was easier for the audience to understand. In the past, the list of misunderstood physical and mental characteristics (disabilities) was endless; perhaps attributing the cause of these disabilities to evil could be seen as justifiable from a social, physical, and knowledge-based time line. John Quicke (1985) said:

“There are, latent to the dominant culture, ideas about handicap and disability from an earlier period which still have considerable force. An example is the notion, which runs through the history of Western civilization and is legitimated by various religious teachings, that disability indicates possession by the devil or by an evil force, or is the outcome of evil doing” (p. 3).

Feelings of guilt sometimes led to the rationalization that disabled persons hated the nondisabled and were jealous of them (D. King, 2007). That supposed resentment and hate towards the able-bodied alone has been enough reason to portray a character as evil. Crime fiction such as *Doctor No*, *Doctor Strangelove*, and *Hookman* commonly include revenge as a motivation for some acts by the disabled character. Disabled villains, raging against their fate and hating those who have escaped affliction, often seek to retaliate against those who are not disabled. In *Hookman*, the main character is a double-amputee sniper who lost both hands in a foiled bank robbery. He pledged to avenge his maiming by killing a police detective.

Another *Hookman* is a monster in the book *Elfwood*. He becomes a “monster” because he undergoes physical changes and grows a hook instead of his normal hand.

Even when disabled people were not actually evil, they were, and often are, to be feared or treated as less than human, as reflected by a caregiver in the 1970s who worked in a facility for the mentally disabled and is quoted as saying, “I've always said that what we need here is a vet, not a psychiatrist” (Shearer, 1981, p. 82). A classroom textbook used during the mid-1960s at California state hospitals warned nursing students “do not to refer to your charges as vegetables, no matter how you feel about the patient” (Abel, 1960, p. ii). The Otherness of disabled people was seen as dangerous; one dealt with them at one's own peril.

From Blatant to Subtle

We have gone from a nation where telephones were a novelty and automobiles were rare to a nation where 90% of the houses have television and more than half of the country has access

to the internet in their homes.² It is easy to assume that, because the physical/social environment has changed dramatically over the last century, literature has changed as completely. We have seen this is not the case. While most contemporary work is not as blatant in casting people with disabilities into the role of evil or sub-human, these ideas are still present in a more subtle form.

Clinical psychologist Dr. Robert J. Jackson (personal communication, August 26, 2002) says, “We attach bad and evil to ugliness and we attach good to the more perfect.” For example, Faulkner often portrays disabled persons as a curse, or punishment against their families. In *The Sound and the Fury*, Faulkner wrote that Benjy’s mother thought that he was “punishment.” People in Faulkner’s fiction who see others as “punishment” tend to personify a destructive force. That means they act in a self-centered way using the disability of another as an excuse for their inability to cope (K. Richardson, interview, June 12, 2002).

Linguistics

American writing is, of necessity, based on the culture and language of the arbiters of the nation and its education. Linguistic theory says that it is difficult to have an idea, let alone express it, without the vocabulary to think about the idea. Limited vocabulary languages often give us great poets, but not as many scientists, who must have a large pool of precise words to communicate their results. T. Eagleton (1983) said, “The meaning of language is a social matter; there is a real sense in which language belongs to my society before it belongs to me” (p. 71). Marshall McLuhan (as cited in Anderson, 1991) argued that the introduction of print-based information technologies—whose economies of scale demand homogeneous spelling, grammar and vocabulary—inevitably produces a sense of nationhood. In the same vein, McLuhan (as cited in Anderson, 1991) wrote, “There cannot be nationalism when there has not first been experience of a vernacular in printed form” (p. 218). Thus, there is a tendency to tap into that pre-existing societal language even as the nation continues to evolve intellectually because it is part of the nation’s psyche.

In order to change ideas and express new ones, new vocabulary must be created or, at least, existing vocabulary must be altered. In that regard we must turn to the medical model to explain cultural changes:

“The medical model remains the typical perspective not only in medicine, rehabilitation, special education, and other applied fields, but in the social sciences and humanities as well. As a result, traditional academic study represents disability as a defect located in individuals that requires corrective treatment. This approach not only medicalizes disability, it thereby individualizes and privatizes what is in fundamental ways a social and political problem” (P. K. Longmore, 2003, p. 4).

Much of the new vocabulary and cultural ethos, the language of society and literature, comes from the sciences and the medical model because most of our society now accepts that mental disability can usually be traced to genetic, physiological, or situational roots (Good, 2008). With the understanding of the causes of physical and mental differences, there comes more understanding and acceptance by society in general and the literary community in particular.

The new science-based understanding is reflected by authors and publishers because the larger cultural context affects them just as it does the rest of society.

Even when disabled people are presented in a positive light, they are often stereotyped. “An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment only becomes a disability when the ambient society creates environments with barriers— affective, sensory, cognitive, or architectural” (Davis, 2002, p. 41). Most fiction presents disability as catastrophic or sad or a burden for the person affected and those around them. Many novels feature disabled characters who must adjust to their lives. While this is a reasonable theme, most of these novels portray that life as a great struggle, hateful to the individual and far less rewarding than the previous, nondisabled, life. Biographies often laud people with disabilities who have “overcome” their situation.

Superstition Plays a Part

The fight against stereotypes has been, and will continue to be, a difficult battle. One reason is that it is easier to stereotype a group of people than to have to deal with them individually. The people with disabilities are not alone in this. However, the stereotypes of disabled people go back into the history of our culture and much of that history portrays the disabled as monsters (Stiker, 1999).

Back through the mists of antiquity, the idea of monsters has been intertwined with superstition: werewolves and vampires stalk the land; the planets influence our lives; black cats portend disasters; certain dates are propitious; certain numbers are to be avoided; and physical disability is a reflection of wrongdoing (Stiker, 1999).

The Disabled as Lab Animals

Throughout early history in the United States, a baby born disabled was often left to die. The disabled were a menace, an evil stalking beast that was going to devour society (Pernick, 1992). Additionally, one was free to use both the physically and developmentally disabled, like animals, for human experiments. In 1966, Harvard medical professor Henry Beecher published the article “Ethics and Clinical Research” in the *New England Journal of Medicine*. Beecher’s (1966) article cited a series of cases in which human experimentation created, in his opinion, ethical problems of the first order. He cited the case where live hepatitis viruses were fed to residents of a state institution for the developmentally disabled in order to study the progression of the disease under “controlled” conditions as one example. Mainstream medical researchers claimed that a great deal of good could (and had) come from human experimentation. “Even if a few lives were sacrificed along the way, humanity would be better for it in the long run” (Hoeffler & Kamoie, 1994, p. 120) seems to be a fair representation of the prevailing ethos.

Along with that assumption was another: that the only value developmentally disabled persons (and some physically disabled persons) had was as sort of lab animals. In the years that followed Beecher’s revelations, religious and activists groups such as the National Legal Center for the Medically Dependent and Disabled, have come to play an important role as sources of policy restraint in the treatment of the disabled (National Legal Center for the Medically

Dependent and Disabled, 1994). Simply the need for these kinds of pressure groups to inform public policy is indicative of how the attitudes concerning the value of some human lives still affect our societal view and, by extension, our literature.

Disability as a Tool

The shelves of bookstores and libraries are lined with copies of *Midnight Cowboy*, *One Flew Over the Cuckoo's Nest*, *Flowers for Algernon*, *Rain Man* (Johnson & Levinson, 1988) and dozens of other books that use the disabled to frighten, amuse, or sadden readers. Rare indeed is a novel's central character disabled unless there is an overriding purpose for that disability, a purpose that drives the story, a purpose that tugs at the heart, educates, frightens, or provokes laughter (Nelson, 2003). It is as if authors see the disabled as a type of prop. The Russian author Anton Chekhov established the idea that every element in a play or story must be necessary to the story: if there is a gun hanging on the wall in the first act, it will fire in the third act. In the case of a disabled character, it seems the handicap must be either necessary to the story, or at least a prop that must be used. For example, author Jean Jenkins said that she chose a disabled young man as a primary character in a young adult novel because:

"I needed somebody who was appealing but vulnerable. And also its part of the crux of the whole story that the main character, whose name was Dee Dee sees this really 'hot' guy in a really 'hot' car. She falls for him. She's seen him around town and everything, but doesn't find out until the first day of school when she encounters him in the hallway that he's disabled. So it becomes an issue at that point" (interview, 2002).

Can we ever divorce ourselves from a character's disability? Would the author truly want us to? The answer to both questions is: probably seldom. There are a few books where a disability is treated as such a minor part of the characterization that it is of minimal importance, but not many. A disability is part of the character, so to ignore it would be to disregard a substantial piece of the characterization. Authors do not want a reader to forget a character's disability any more than they want a character's sex forgotten. Otherwise why put it in the story? If minimizing the importance of the disability is necessary or desired, then even achieving that end is an act based on the disability.

Secondary to the disability driving characterization is our society's expectation that all the main characters be near physically perfect.

"When you see a novel, whether it be a romance or detective or mystery, or whatever, and let's say it's a female main character, are they normally 275 pounds with crooked teeth, and crossed eyes and blemished skin, a big pot-bellied stomach? No. So we have this perfection in our characterization in the novels. At least in this century . . . the disabled are usually secondary characters" (R. J. Jackson, personal communication, August 26, 2002).

Nevertheless, if, as M. Eagleton (1986) says, "literature, by forcing us into a dramatic awareness of language, renders objects more 'perceptible'" (p. 4), then indeed including the disabled in literature is of paramount importance. The question is, what is the perception now,

and is it changing for the better? Do authors use disabled characters as emotional hostages, for emotional catharsis, to be politically correct, or because they are necessary to the story? Is the disability necessary to the story? Why? Would the story be as good without the disability?

American Literature: Driven by Emotion and Character

The physically or mentally impaired person has consistently been used as the “other”: the person to who other characters react, emphasizing that someone else is good or evil, or as an excuse for the creation of their own inner world. In many contemporary novels, characterization is often based on reaction and disabilities help create the matrix for that reaction (Thomson, 1997).

Reaction is usually emotion-driven, whether it is on stage or within the pages of a novel, and disabled characters, or the disabilities themselves, can help a writer evoke emotion. American literature is distinguished from English literature in part because it is the norm to seek reader identification with the protagonist in a story and seek or emphasize emotional reaction against a villain. As Mason (1988) said:

“Novel, poem or short story, even the briefest of forms in modern American literature there is an immediate appeal to the senses and evocative descriptions: ‘To the red country and part of the gray country of Oklahoma, the last rains came gently, and they did not cut the scarred earth. White-maned, wide-throated, the heavy-shouldered children of the wind leap at the sea-cliff (Jeffers, 1). . . .’ These descriptions are the introduction to the works in question. They are part and parcel of the emotionality of American literature.... Besides the sensual, American literature is also driven by the characters themselves more often than plot. We are asked to identify with the protagonists and respond to the antagonists in ways British literature seldom does. As a result, the characters are often more broadly drawn in American literature” (pp. 12–13).

During a recent speech at the University of California, Mason (2003) added the following:

“Even disabilities (in American literature) are often over-the-top. Aboulia isn’t a major player while the just-as-rare Osteogenesis Imperfecta is the core of a major motion picture. It is no fun to have a character who does nothing, but someone who can’t even be born without shattering into pieces evokes emotion simply in its description.”

It is this focus on emotionality that underlies the selection of a disabled character by some American authors. Many authors use them one time, and then merely as tools to invoke horror, fear, disgust, pity and a plethora of other negative emotions. The use of a disabled character is often the means to a mean end and that process often requires the disabled character to be the monster or the villain. There are three primary reasons the disabled have been used as villains: ease, superstition and as a reflection of a limited reality.

Instant Villains: The Easy Way Out

Disability has often been used as a melodramatic device to create the emotionality Dr. Mason discusses above. Among the most persistent is the association of disability with evil and wrongdoing (Thomson, 1997). As noted earlier, deformity of body symbolizes deformity of soul. Physical handicaps are made the emblems of evil. P. Longmore (1987), himself disabled, provides categorizations of disabled representation in media based upon symbolism, characterizations, and stereotypical narratives—a number of which echo the themes discussed here:

- disability as an emblem of evil
- the disabled as ‘monsters’
- disability as the loss of one’s humanity
- disability as total dependency and lack of self-determination
- the disabled as being maladjusted
- disability as a compensation for some other special gift/power
- disability leading to courageousness or achievement
- the disabled as sexual menace

Even psychiatrists, in their earnestness to try to educate using literature as a medium, can be guilty of the perpetration of the disabled-as-evil stereotype. Charles Atkins (1998), a psychiatrist, wrote the mystery novel *The Portrait* in order to educate people about mental illnesses. His protagonist is a painter with bipolar disorder who must untangle a mystery while working to control his own disorder. Unfortunately, the villain is mentally ill as well, and presented in stereotypical fashion. Likewise, another Atkins (1999) novel, *Risk Factor*, explored youth violence by connecting that violence with mental illness.

Carroll (1990) said that monsters are horror made visible. Carroll, among other attributes, said that monsters have the following attributes:

- Monsters are deformed and ugly.
- A monster’s physical deformities reflect thematic conflict—good vs. evil, for instance, or specific kinds of corruption.
- Monsters can be . . . possessed, incomplete. They are beings who are not like us.
- Monsters are unnatural according to a culture’s conceptual scheme of nature.
- Monsters violate the scheme of nature.
- Monsters challenge a culture’s way of thinking.

While Carroll was writing about non-human monsters such as Godzilla or werewolves, one can easily see how all of these attributes apply to many depictions of people with disabled in literature. The most obvious feature of monster characterizations is their extremism. The physical disabilities portrayed in literature typically involve disfigurement of the face and head and/or gross deformity of the body. As with the criminal characterization, these visible traits express disfigurement of personality and deformity of soul. Once again, disability may be represented as the cause of evildoing, punishment for it, or both.

According to P. Longmore (1987):

“The depiction of the disabled person as “monster” and the criminal characterization both express to varying degrees the notion that disability involves the loss of an essential part of one’s humanity. Depending on the extent of the disability, the individual is perceived as more or less subhuman” (p. 135).

Such depictions also exemplify the “spread effect” of prejudice. The spread effect assumes that an individual’s disability negatively affects other senses, abilities, or personality traits, or that the total person is impaired. For example, many people shout at people who are blind or don’t expect people using wheelchairs to have the intelligence to speak for themselves (Office of Disability Employment, n.d.-a). Focusing on the person’s abilities rather than his or her disability counters this type of prejudice (Office of Disability Employment, n.d.-a). The stigmatized trait assumedly taints every aspect of the person, pervasively spoiling social identity.

The spread effect carries over into the attitude that there is a loss of self-control and thus as endangering the rest of society (Office of Disability Employment Policy, n.d.-b). The dangerous disabled person is not necessarily a criminal or a malevolent monster, but may be a tragic victim of fate, as in Steinbeck’s (1937) *Of Mice and Men*. In that story Lennie is the exemplar of the idea that the specific nature of the disability is moot. Whatever the manifestation of disability, it unleashes violent propensities that usually would be kept in check by internal mechanisms of self-control.

In both horror stories and criminal characterizations, it is often the disability itself, and the resultant out-of-control behavior, that separates and isolates the disabled character from the rest of society. While viewers are urged to pity characters such as Lennie, we are also shown that disability must forever ostracize severely disabled persons from society. For both monstrous and criminal disabled characters, the final and only possible solution is often death, a fitting and just punishment in the context of the story. For sympathetic monsters, death is the tragic but inevitable, necessary and merciful outcome.

This acceptance or rejection of good and evil based upon appearance is pandemic in our society. Varni and Setoguchi (1996), from the Department of Psychiatry, University of California, San Diego, School of Medicine, noted that:

“In our society (and perhaps more generally, in our species), physical attractiveness represents a highly prominent personal characteristic that systematically influences interpersonal interactions, perceptions, and inferences about an individual’s ability. This ‘beauty-is-good’ prejudice has been found across all age groups” (p. 201).

Beyond mental illness, there are those whose bodies and faces are so far removed from what people are used to seeing, so far from any semblance of normalcy, that they represent unsettling or frightening possibilities to many.

Abby-Normal Is Just a Name

Like any identifiable group, whether ethnic, religious, or social, a percentage of individuals with disabilities break the law, are homeless, or abuse various substances. However,

the vast majority live, love, eat, sleep, work, get sick, and get well like anyone else. Where are these normal disabled people in literature? Images of these ordinary people are so rare that when they appear they are fodder for television, newspapers, and magazine articles (Fielder, 1996). Marlee Matlin, the Academy Award winning star of the movie *Children of a Lesser God* (Palmer & Haines, 1968) made headlines because she was a deaf actor even before winning the prize. The *Denver Post* found it necessary to use the headline “Princess’ Regales in Tale of Regals: Handicapped Actors’ Troupe Hits Mark in Musical Comedy” when reviewing the cast of the acting troupe PHAMALy appearing in *Once Upon a Mattress*—a play which has nothing to do with disabilities (Moore, 2002).³ The Academy of Motion Picture Arts and Sciences in 1947 gave Harold Russell, who lost both his hands in World War II and was the star of *The Best Years of Our Lives* (Goldwyn & Wyler, 1946), not only the award as Best Supporting Actor, but also an Honorary Oscar for bringing hope and courage.

Being Ignored is not Necessarily the Problem

In discussing the portrayal of disabled people in American literature, one can almost be tempted to ask, “What portrayal?” Yet that would be the wrong question to pose because, indeed, disabled people have been included. Books have had a disabled central character or the hero, such as Steven King’s (2001) *Dreamcatcher*, Susanna Kaysen’s (1993) *Girl Interrupted*, and of course, *Forrest Gump*, by Winston Groom (1986). Indeed, literally hundreds of disabled characters appear in literature. Certainly, in some books and short stories, supporting characters, whether victims or villains are present as a foil for the author to use in order to evoke emotion. To say that disabled people have been ignored would be incorrect. If, in the literature of the United States, the plays and scripts of its theatre, television and movies are included, one encounters countless disabled characters. Characters with all sorts of disabilities include victims rendered helpless by disability, horror stories whose antagonists are monsters because of their physical problems or appearance, and a plethora of disabled criminals.

During the last quarter of the 20th century, minority voices, including those with disabilities, found a place at mainstream publishers. Some of this new openness was simplistic and offered few, if any, answers to the questions they raised.

Opening the Door

To be successful, the writer must allow readers to in some way identify with their characters. In ever-greater numbers, people of different races, colors, heritages, and cultural and religious backgrounds are able to walk into a bookstore, pick up a novel, and find a more personal connection than previously. Unhappily, a person with a disability can rarely read about a sexy spy, a rich business person, a tortured yet sought-after actor, a rock and roll singer, or a working cop in a wheelchair, on a respirator, with short-term memory deficit, right or left hemisphere paralysis, or with any of a hundred other problems that leave them disabled. Where is their identification with a character beyond self? Moreover, where is the nondisabled person going to see persons with disabilities as whole people with complete lives?

Instead of portraying disabled individuals in the many roles they actually play in our world, literature tends to stereotype their roles. Dr. Robert J. Jackson says:

“I think that the disabled are often portrayed as isolated, secluded although in many cases I see that they might have someone who takes care of them. They don’t live alone. They portray them as dependant, maybe they had money, or they weren’t always disabled. But now they’re disabled, recluses. They are portrayed as bright, especially the blind. They tend to think of the blind as insightful and wise, right? That’s the wise group.

I’ve noticed that with the wheelchair, they tend to portray those guys as alcoholics, angry, rebellious. Then in many of the books I’ve read they convert them once they’ve been given something meaningful to do by the main character. They’re never the main character. So wheelchair is strong and angry, rebellious, but they make it. They turn it around. . . .

How often do you see stroke victims portrayed in novels? Not often because now you’re getting into the cognitive. People don’t want to hear about dementia. People’s greatest fear is dementia. So if you’re a novelist you write into a Steven King type fear, you don’t want to write into a fear personalized to that level” (personal communication, August 26, 2002).

This is the time of political correctness, the raising of social consciousness, racial, social, and sexual correctness, and laws prohibiting most forms of discrimination, sexism, ageism, and segregation. Additionally, the federal Americans With Disabilities Act, along with state and local laws regarding nonexclusion of the disabled, is helping to bring about increased and, often, new awareness of the person living and coping with a disability (Cromwell Center, n.d.-a, n.d.-b).

Whether literature leads or follows national trends is a debatable point. Change is almost always evolutionary, not revolutionary. Knowledge evolves from what exists. As Sir Isaac Newton said, “If I have seen further it is by standing on the shoulders of giants” (as cited in Bartlett, 2002, p. 290). However, if we allow ourselves to climb to the exalted heights of those who have gone before us, we may glimpse the future and may help mold it. Literature has already begun to change, and is continuing to evolve, with regard to how the disabled are portrayed. It is rising above sympathy, and that is a direction that contemporary literature can afford to take.

Conclusion

With the slow beginning evident in modern literature, through the hesitant steps in the early 1940s, the portrayal of disabled people seems to be evolving gently into the mainstream. That is not to say that its arrival is complete, but with works like *The Stand*, *A Dangerous Woman*, *The Heart is a Lonely Hunter*, *One Flew Over the Cuckoo’s Nest*, *Midnight Cowboy*, and *Rain Man* we are seeing greater public acceptance of the previously side-lined and disenfranchised mentally and physically disabled person as well as greater risks taken by authors who choose these individuals as central characters.

Raymond Babbitt, the central character in *Rain Man*, is not necessarily a sympathetic character, regardless of whatever awe his mathematical abilities may invoke in the reader. As

his mannerisms become annoying, the reader can understand his family's impatience, and is disturbed by the inconsistency of his abilities/disabilities.

In *Children of a Lesser God*, we sympathize with Sarah and James in their quest for each other, while enjoying the fact that she is not a timid little person who uses her disability as an excuse to garner pity. Certainly she uses her hearing loss as a controlling mechanism, but that is a survival mechanism rather than an abdication of life. This is a strong woman, who seems real to us.

The sense of humor that Ken Kesey manages to impart to Randle P. McMurphy is rare in literature with disabled characters. Yet McMurphy's ability to know the absurdity of many of the situations in his institution, absurdities the reader fully sees, is pronounced only because of the situation. The American public fell in love with this character. Even though we are not sure if McMurphy is mentally disabled or not, or is simply feigning a disability, he is a man who fights the establishment, is independent and, yes, tilts at windmills using a disability.

There is still use of sentimentality, pathos, and fear of disabled characters in literature. While those portrayed in these ways are often central characters, their disability is usually also just as central. We seem to be approaching the point where this is true of most literature, but we have not yet reached that point. From all indications, literature is not suffering due to this more realistic approach, but rather is expanding with ever more verisimilitude. It is becoming ever more inclusive. Eagleton is correct: reading is more of a boudoir than a laboratory. In reading we are intimate, we are close, we hold. Whether we love, hate, or are angered when we read, if the work is successful, it moves us. We learn not only cerebrally, but also emotionally, when we pick up a book. Other people's lives, homes, loves, tragedies, and successes are ours to learn from, relate to, and share. T. Eagleton (1983) noted that:

“...The strength of Leavisian criticism was not that it was able to provide an answer, as Sir Walter Raleigh was not, to the question, why read Literature? The answer, in a nutshell, was that it made you a better person” (p. 35).

If literature can make you a better person and create a richer culture, might not greater, more inclusive literature create an even richer environment? We do know that the inclusion of valid feminist, gay, lesbian, African American, and so many other under-represented characters in the canon of American literature, has widened its attraction for all readers, so that the inclusion of properly depicted disabled persons can only increase that readership again (Andrews, 1998). Hopefully, the scope of literature will be expanded with fewer stereotypical characters in more believable situations. This is already happening as authors search for ways out of the old patterns of portraying the disabled as either fearsome or evil. That search must continue and, if it does, eventually readers and writers both will realize that the disabled are not the “other.” This does, indeed, require a new way of looking, but only by looking do we see.

Miles Beauchamp, Ph.D., is Assistant Professor of Communications in the Marshall Goldsmith School of Management and Shirley Hufstедler School of Education at Alliant International

University. He is also Associate Editor and columnist at the Asian Journal and past Chair for the Commission on Disabilities, El Cajon, California, USA.

Wendy V. Chung, Ph.D., is the Program Coordinator for the Communication Program in the Marshall Goldsmith School of Management at Alliant International University. Her publications, including her text on Ethnicity and Organizational Diversity, focus on the impact of diversity on organizational culture and climate. Her interest in issues of disability evolves from her research interest in the issues of cultural diversity and communication.

Alijandra Mogilner, President of Faucon International, holds a Ph.D. in anthropology and is the author of *Children's Writers' Word Book* (Writer's Digest Books) and specialized texts for English as a second language. She has worked with English development programs in Canada, China, and several countries in Africa.

Correspondence concerning this article should be addressed to Miles Beauchamp, Alliant International University, 10455 Pomerado Rd, San Diego, CA 92131-1799
E-mail: mbeauchamp@alliant.edu

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End Notes

¹ According to the Bowker Agency, which assigns ISBN numbers and does research on what is being published, there are about 500 companies that have published at least some juvenile literature pertaining to the disabled. According to the Society for the Disabled, this has grown from less than a dozen 5 years ago.

² The Face of the Web, Year 2002 study of Internet trends by global marketing research firm Ipsos-Reid, which has been tracking Internet awareness and usage around the world since 1999.

³ PHAMALy: Physically Handicapped Amateur Musical Actors League, a company of actors with a wide range of physical and mental disabilities.

A Way Forward: Presenting a Post-modern Framework for Disability
Rachel Carling-Jenkins, Ph.D.
Monash University, Australia

Abstract: People with disability continue to be engaged in a rights struggle which is reinforced through processes of modernity. This paper reviews the modern framework and its far-reaching effects in influencing understandings of disability, using the Australian experience as an example. An alternative post-modern framework is then presented in contrast. A post-modern conceptualisation of disability is presented as a way forward for understanding disability and for application to disability studies and research.

Key Words: modern, post-modern, disability rights

A Modern Framework

Within modernity, binary notions that support an oppressive discourse are created and maintained. A binary involves two distinct, often polarised, elements. Position matters within binaries where people are categorised as either privileged or “other.” Within the position of privilege, people are politically and economically esteemed and supported by hegemonic advantage. The “other” are thought of as deviant, different, even undesirable, and are subsequently made inferior.

The maintenance of these binary notions creates a veil of concealment over the relationship inherent within such positionings, where categories of black/white, straight/gay, male/female, rich/poor, and disabled/abled hide the relationship of oppression and privilege between people within these groups (Carling-Burzacott & Galloway, 2004). Modernity separates people with disability as “other,” framing and defining them individually, excluding them from full participation in society, medicalising and commodifying their bodies and lives, and imposing deficit models with the purpose of reinforcing the existing hegemony¹. Disability in Australia has long been understood within such a deficit model produced within modernity. This understanding has subsequently infiltrated and undermined disability research, studies, and practice.

A modern framework for disability studies and research is supported by individual and medical models of disability--models that rely on meta narratives² of deviance, tragedy and the separation of “normal” from “abnormal” (Corker & Shakespeare, 2002). At the core of this framework is an oppressive discourse. Within disability studies and research, binary notions adopted through modernity’s influence result in the elevation of the privileged researcher who uses his/her position to accrue social, economic, political and linguistic privilege over people with a disability as the “other.” In this instance, researchers’ needs are promoted and advanced at the expense of people with disability. Exclusion is reinforced and consideration of systemic issues such as discrimination is nominal at best (Newell, 2005). Extreme examples of this are often cited such as the medical research in Nazi Germany where people with disabilities were exploited, experimented upon, and often exterminated.

Australian Struggles rooted within Modern Framework

Australia does not have a proud disability history. Historical struggles can be traced to the early settlement of Australia by European invaders who segregated the “insane” on hulks (large ships used to transport convicts from England) until buildings could be erected to accommodate them (State Records NSW, 2006). People with a physical disability were portrayed in terms of a “lack of worth” throughout Australian history, which depicted them as invalids and as defectives. The Eugenics movement had a strong influence in Australia in the early 1900s through to the 1930s, where widespread practices of Social Darwinism separated people with disability from definitions of humanity (Carlson, 2001).

Today, within Australian society, people with disability continue to be located as “other” and therefore remain stuck within modernity. Australians with disability are more likely to be imprisoned, institutionalised, or assaulted, receive welfare benefits, or to be restrained, sterilised, or aborted (Bolt, 2004; Dowse, 2004; Frohmader, 2002; Sherry, 2008). In contrast, their non-disabled counterparts are more likely to be found in places of higher education, in their own homes, and in paid positions of power, including positions within the disability sector (Leipolt, 2005; Goggin & Newell, 2005).

Australian disability history is characterised by objectification and control supported by tyrannical medical and professional discourses which imposed regimes, restricted opportunities, and reinforced poverty (Carling-Jenkins, 2008). People with disability in Australia have been fragmented, institutionalised, marginalised and commodified as a result. In addition, there has been no cohesive movement of influence, power and identity to support them in their rights struggles (Newell, 1996; Russell, 1998). Research into the positioning of disability and the Disability Rights Movement in Australia, revealed that the historical and continuing struggles of people with disability have been reinforced through processes of modernity (Carling-Jenkins, 2008). These processes were evident through four main themes: the denial of citizenship; segregation within institutions; living on the margins and the ‘disabled body’.

Denial of Citizenship

Within Australia there has been a disparity between the experience of the privileged who enjoy full citizenship rights without question (i.e., full political and economic enfranchisement and full participation in society) and people with disability (as the “other”) who have routinely had their humanity and capacity questioned and cost-effectiveness calculated through criteria not imposed upon people without disability (Cocks, 1996; Goggin & Newell, 2005; Jolley, 1999; Meekosha, 2000). Such questioning and calculation has led to the denial of full citizenship. While historical seclusion within institutions represented a physical separation from these rights, post-deinstitutionalisation Australia continues to routinely deny full citizenship to many people with disability.

One example of this denial is evident through the separation of privilege and other which exists within the Australian system of political enfranchisement where different rules apply to different people. This was codified originally within the *Commonwealth Franchise Act 1902* which denied voting rights to people judged to be of “unsound mind” (Goggin & Newell, 2005). There is a continued denial of the right to vote for many people with an Intellectual Disability,

Acquired Brain Injury, or with a mental illness for example (Cocks, 1996; Goggin & Newell, 2005). In addition, people with physical and sensory disabilities are faced with inaccessible voting processes and procedures (Physical Disability Council of Australia, 2000). Subsequently, people with physical disabilities have been asked to vote in venue car parks or asked to post their votes, while people with sensory disabilities have been forced to use a third party to record their vote (Crane, Clark, & Simpson, 2005; Goggin & Newell, 2005; Ozdowski, 2002). Each of these solutions has raised concerns regarding the privacy of the secret ballot system.

Another example exists within the widespread practice of routine exclusion from immigration to Australia on the basis of disability. Provisions are made for this under the Federal Disability Act and under migration laws (*Disability Discrimination Act*, 1992; Jolley, 1999). Australian immigration policies have been described as having a “eugenicist prologue, with close connections made between physical appearance, cultural capital and moral hygiene” (Jakubowicz & Meekosha, 2000, p. 6). Children and adults with disability are assumed to be a financial burden to the Australian community, and thus entry to such applicants is routinely denied (MDAA, 2005). In 2000, Shahrzad Kiane, a man granted refugee status, died as a consequence of setting himself on fire on the steps of the Australian parliament, after his attempts to have his family immigrate to Australia were rejected on the basis of one of his children having a disability (Goggin & Newell, 2005; MDAA, 2005; Newell, 2005). Kiane had reportedly worked for six years to have his family join him in Australia, but the government refused his application on the basis that his daughter’s disability would be too much of a drain on the health system (MDAA, 2005; Newell, 2005).

Segregation within Institutions

Australian institutions represented sites of total, long-term segregation from society which allowed the privileged to gain full control of public spaces, while people with disability were forced into an economic, political, and social form of invisibility. A modern framework which advocates the active favouring of the privileged at the expense and devaluation of individuals who are “othered” underlies and supports such segregation. Many different institutions were established, including The South Australian Institution for the Blind, Deaf, and Dumb for destitute people with sensory disabilities (1874), Woogaroo Lunatic Asylum for people with mental illness (1878), Kew Cottages Idiot Colony for people with intellectual disability (1887), Societies for Crippled Children for children with polio or tuberculosis (1929 – 1951), Janefield Colony for mentally deficient children (1937), and the Spastic Children Society of Victoria for children with cerebral palsy (1948). These institutions received a legislative base in such acts as the Lunacy Act 1928, the Mental Hygiene Act 1933, Mental Health Act 1959, and the Health Commission Act 1977.

The impact of such segregation included exclusion from public spaces, such as exclusion from the workforce. Within institutions, people with disability were placed outside of the receipt of welfare benefits and denied many opportunities to attain skills, including basic life skills. Institutions imposed medical, custodial, and protective models of care. Mass institutionalisations occurred, initiated through the medical framing of people with disability as biologically sick, dependent, and deviant. Parents were encouraged to leave their “sick” babies with disabilities such as Down Syndrome and cerebral palsy in hospitals and not take them home. Infants were

then ‘cared for’ within large hospital settings where staff were encouraged not to embrace or comfort them (McDonald, 2009).

Many Australian institutions have been exposed as sites of exploitation, abuse, and neglect. People were locked in cages, exposed to unsanitary conditions (such as maggots found in feeding tubes), had their teeth removed to prevent biting, were commonly raped, routinely sterilised, and were denied both medical attention and pain relief (e.g. regular pap smears or prostrate checks were not offered, and reports of children with life threatening diseases left to scream without comfort or relief have been recounted) (Grace, 2005; Dyke, 2004; Meekosha, 2000; McDonald, 2009).

Living on the Margins

The process of deinstitutionalisation, rather than heralding a new era of community inclusion and participation, introduced fresh challenges for people with disability in Australia, many of whom were moved from one form of segregation to another form on the margins of society. This exemplifies the continued influence of a modern framework – and the binaries which work to separate the privileged from the “other.” Within Australia, many people with disability were displaced without adequate resources—either personal or communal—to support their transition from institutional care. The decision to initiate de-institutionalization was based not only on the demand for social inclusion, raised through the International Year of Disabled People (IYDP), but also “reflected the greater use of pharmaceutical control agents...and the fiscal crises of the states unable to maintain high standards of large scale institutions” (Hallahan, 2001; Jakubowicz & Meekosha, 2000, p.3). This displaced people into the community which was ill-equipped, under-resourced, and inaccessible both physically and economically. In addition, the community was without a commitment to enhancing the lives of people with disability (Hallahan, 2001), and exposed many people with disability to further abuse, exploitation, inappropriate living arrangements, and homelessness (Burdekin, 1993).

In this climate, people were often isolated from each other, forced to adopt “normal” social roles, reframed as clients rather than patients, and denied their identity as disabled people. Many were placed in group homes which were often run as private ventures with a one-size-fits-all mentality (McVilly & Parmenter, 2006). Social workers and other health professionals became the experts over disability, further denying people with disability the freedom to create identities for themselves. This further exemplifies the continued influence of a Modern framework and the binaries which work to separate the privileged professional from the “other” who is denied the role of expert within his or her own life.

“Disabled Body”

The body of people with disability has historically been, and continues to be, a site of oppression in Australia. The “disabled body” is defined and controlled by the privileged, and subsequently placed in a paradoxical position. For example, people with disability are framed as an inspirational super cripp who has overcome many challenges to achieve a goal; or as a tragic burden to be pitied, medicalised, treated, and cured (Shapiro, 1994; Egan, 1998). Another example lies in the portrayal of people with disability as either a harmless child, asexual,

innocent, eternal child, needing to be protected and looked after; or a dangerous criminal who is oversexed, and from whom society needs protection (Perry & Whiteside, 2000).

The “disabled body” is used as a derogatory descriptor within Australian society, where terms such as “crippled” and “deranged” continue to be an accepted part of colloquial language (Mowbray, 2005), as well as being employed within parliamentary discourse (Goggin & Newell, 2005).

The “disabled body” continues to be vulnerable to abuse—both within the womb and throughout life. The privileged continue to control the lives of people with disability, claiming the domain of medical cures and holding the role of professional gatekeeper by controlling access to resources such as income support, accommodation, and equipment aides. People with disability (especially babies and children) are often denied simple life-saving procedures such as transplants—rejected on the basis of pre-existing disability (Mowbray, 2005).

A Post-modern Framework Alternative

This application of a modern framework to the history of disability in Australia, led me to question: what is the alternative? I began to consider elements of a post-modern framework, in contrast to those contained within a modern framework, using them to reframe disability as a modern then a post-modern concept (see [Table 1.1](#) developed by Carling-Jenkins, 2008).

Table 1.1 Disability as a Modern and Post-modern Concept

<i>Elements</i>	<i>Modernity</i>	<i>Disability as a modern concept</i>	<i>Post-modern</i>	<i>Disability as Post-modern concept</i>
<i>Economy</i>	Manufacturing based economy	Commodified	Post material interests	Considered outside of economy
<i>Knowledge</i>	One truth	Defined by dominant	Many or no truths	Defined in many ways including by people with disability themselves
<i>Subject</i>	Autonomous, transcendental subject: unified, centred sense	Defined externally, binary notions	Fragmented, de-centred sense of self, Multiple,	Rejection of functional definitions, Focus on

	of self		conflicting identifies	identity
<i>Reality</i>	Objective reality, Logic, science and reason	Discussed in scientific, economic, medical, individualized terms	Socially constructed, Subjects created by social world, Subjectivity	Socially constructed reality imposes barriers and defines disability

References: Berger, 2003; Corker & Shakespeare, 2002; Fitzpatrick, 2001; Giddens, 2006; Giddens, Duneier and Appelbaum, 2007; Irvine, 1998 as cited in Berger, 2003; Kincheloe & McLaren, 2003; Oliver, 1993; Rader & Rader, 1998; Solomon, 2001, as cited in Berger, 2003.

Economy

Consideration of *economy* (see [Table 1.1](#)) is integral to the modern framework. Modernity was characterised by a shift from an agrarian economy to that of capital (Carling-Burzacott & Galloway, 2004). Disability as a modern concept must therefore be conceptualised within manufacturing terms, as exemplified in the treatment of people with disability as objects within medical and later within professional systems. The modern element of economy offers a limited, narrow understanding of disability.

In contrast, a post-modern framework focuses on post material interests (see [Table 1.1](#)). Post-modernity emerged as a school of thought, initially in reaction to modernity in the late 1970s, including a transformation from mass production to information technologies; a shift towards global rather than national economies, with an accompanying weakening of the nation state as a local regulator; and a decline of class politics and a subsequent rise in new social movements (Giddens, 2006). This shift removed disability from being an individualised economic consideration and invited an exploration of definitions of acceptance outside of the economy. Disability as a post-modern concept embraces the complex, interactive dynamics of disability. The implication of this framework is particularly pertinent to people with severe developmental and physical disabilities who, under the modern framework, have been ignored for their apparent lack of economic contribution. Historically, this led to routine institutionalisation.

Knowledge

A modern framework focuses its understanding of *knowledge* (see [Table 1.1](#)) on one truth, defined by the privileged. This truth for people with disability has involved the imposition and maintenance of essentialist descriptors, limiting the power of people with disability to claim anything other than these restricted definitions for themselves, as exemplified within each of the four themes in the previous section. Socio-politically these descriptors have been used to “rationally” explain the inferior health, economic, political and social status of people with

disability. Operating within this modern framework, disability is conceptualised by hegemonically esteemed groups who claim a position of social, economic, political, and linguistic privilege at the expense of those people with disability who were subsequently disenfranchised (from the polity) and dispossessed (of resources including those of psycho-materiality).

A post-modern framework portrays knowledge as embracing many or no truths (see **Table 1.1**). Accompanying post-modernity was a shift in emphasis from scientific absolutisms to narratives, and from expert-knows-best to a shared basis for knowledge (see Lyotard, 1979). Within the post-modern framework, definitions give way to descriptions, absolutes give way to fluidity, and constricted narrowed views give way to opportunities for inclusivity. Disability as a post-modern concept is therefore more fluid and less descriptively-defined concept that opens up and explores opportunities for genuine inclusion and engagement in relationship. Disability is conceptualised and defined through multiple identities, including most significantly by people with disability themselves. A post-modern framework enables definitions that explore the paradox of disability (Dempsey & Nankervis, 2006). Knowledge within this framework is a process and a journey, rather than a set entity.

View of Society

Society, as viewed through the modern framework, is portrayed in terms of certainty, progress, absolutisms, and reductionist philosophies (see **Table 1.1**). When disability is considered within such a framework, functional definitions, prescriptive treatments, categorisations, and narrowed operating agendas are imposed. Institutions emerge to segregate people with disability, and strict definitions guide entrance to social systems such as receipt of welfare benefits and immigration.

In contrast, a post-modern framework views society within multiple meanings, ambiguity, diversity, difference, and even contradiction (see **Table 1.1**). A post-modern society is characterised by dynamic and fluid interactions (Giddens, Duneier, & Applebaum, 2007). A breaking up of grand narratives occurs (see Lyotard, 1979). Disability within this context celebrates difference, embraces fluidity, and can be understood in terms of relativity, and social and cultural contexts. This framework emphasises the need for micro theories to understand the nature of “difference” (Barnhart, 1994). Sherry (2008) exemplifies this application of a post-modern framework to disability in his discussion of disability and diversity:

“Disability is a diverse experience. It affects some people’s minds, some people’s senses, other people’s bodies, and so on. Someone who is hard of hearing is likely to have very difference life experiences from someone who is blind, or another person who has a developmental disability. And they all will have different life stories to another person who has a serious mental illness or someone who has end-stage cancer. Even among disabled people, there are huge differences. We need to be mindful of the diversity among disabled people as one of the starting points for understanding any particular disability” (p. 5).

Subjects

A modern framework categorises *subjects*, bounding them within limited binary positionings (see **Table 1.1**). Subjects are autonomous, unified, and have a centred sense of self—external definitions are imposed, accepted, and adopted internally. For disability the implication is that people, both categorised within disability and without disability, are left with nothing but this language with which to define themselves (Carling-Burzacott & Galloway, 2004). Hierarchical social relations where disability is portrayed undesirably are reinforced. A binary positioning of powerful/powerless is perpetuated through the modern framework.

As an alternative, a post-modern framework promotes a more fragmented, decentred sense of self, which accepts multiple, conflicting identities (see **Table 1.1**). This framework frees subjects from the modern binaries and the power relations they perpetuate. Lyotard (1979) explained the mobility of self and the accompanying fluidity of power:

“A *self* does not amount to much, but no self is an island; each exists in a fabric of relations that is now more complex and mobile than ever before... No one, not even the least privileged among us, is ever entirely powerless.”

Foucault contested the traditional (modern) view of power with its equation to control, as well as institutional forms of power (embraced within the modern framework), presenting power as decentred, pluralistic, and mutually constitutive (Racevskis, 2002; Seidman, 2004). The application of this to disability involves the rejection of externally imposed definitions, replacing this with a focus on identity.

Definitions of disability are “unstable and open to contestation” according to Sherry (2008, p. 11) who advocated exploring the nuances, subtleties and contradictions inherent within (a post-modern understanding of) disability, rather than consolidating disability as a fixed identity (as a modern understanding). In addition, a post-modern understanding acknowledges that disability “occurs alongside multiple other identities (such as sexuality, race and ethnicity, socioeconomic status, etc.)” (Sherry, 2008, p. 75). This enables the concept of disability to be freed from essentialist descriptors.

Reality

Reality within a modern framework is ruled by objectivity, logic, science, and reason (see **Table 1.1**). The reality of disability then is couched in scientific, economic, medical, and individual terms. This underlies all four themes previously discussed.

A post-modern framework promotes reality as socially constructed, views subjects as creations of the social world and embraces subjectivity (see **Table 1.1**). Disability within this frame is then considered as involving social construction. The implication is that we are encouraged to embrace subjectivity, and to focus, for example, on the deconstruction of the binaries created within modern society.

A Way Forward

Considering disability within this framework reveals a way forward for conceptualising and understanding disability within disability studies and research. Disability becomes a relationship not a binary, an actor in power not exclusively bound within institutional systems, a complex, multi-faceted dynamic not an entity summarised within narrow functional definitions, a fluid existence (that intersects with gender, religion, and other characteristics) not a static category, and an embrace of difference, identity, diversity and culture not a prison of hegemonically-imposed assumptions. Within this new framework, our focus in understanding disability shifts from categories, functions, oppressive discourses, and reductionist philosophy. Disability becomes understood through actions and relationships that promote a personal, political, and moral commitment to a post-modern conceptualisation of disability. Teaching disability studies from a post-modern conceptualisation becomes a “way of knowing,” an imparting of multiple knowledges rather than a prescriptive schedule of facts and theories (as supported by McRuer, 2009). Within Australia, there are very few disability specific courses, and where such curriculum does exist it is often placed within Faculties of Medicine with an inevitable emphasis on healthcare. Australian publications representing disability studies are also limited (Lester, 2004).

Students of disability studies should be led to identify and confront the binaries, barriers and oppressive discourse surrounding disability within the context of the complex societies in which we live. Conway’s (2009) work on multiculturalism and disability is an important contribution to this way forward, where an emphasis is placed on preparing students to recognise and conceptualise diversity and therefore on the oppression experienced within diversity. Disability studies must challenge the deficit models which individualise disability and actively display a commitment to a post-modern agenda for disability. Jakubowicz and Meekosha (2000) described the role of disability studies as opening-up “ways of examining cultural diversity that cannot otherwise be approached” (p. 1).

The role of disability studies must include the encouragement and facilitation of an alternative world view which embraces disability as a diversity, moving beyond borders and pathology. Such a curriculum needs to be tied to action, or it is “parasitic” (Mackelprang, 2009). Within disability studies the role of academic and activist becomes a fluid category—a partnership (Mackelprang, 2009).

Closely linked to the study of disability is its research. There is a long history of challenging the role of researchers, particularly researchers without a disability. Stone and Priestly (1996), for example, advocated that researchers without disability needed to adopt a position tied to political action, where oppression is challenged and there is a commitment to the emancipation of people with disability through research (see also Priestly, 1997; Swain & Cameron, 1999). Oliver (1999) also stressed the importance of disability research where researchers position themselves clearly within society. The post-modern framework gives disability researchers such a position.

Disability research when conceptualised through a post-modern framework demonstrates a commitment to action. This action involves an active engagement in relationship through challenging the binary of researcher/researched for example. This also means engaging actively with other social movements and interacting with the nexus of oppression (e.g. women with

disability) (see Carling-Jenkins, 2008). Post-modern disability research values studies of the past that propose to prevent repeating mistakes in the future. Disability research should increase consciousness and expand knowledge as defined by multiple dimensions (see Mackelprang, 2009). Post-modern disability research becomes a platform from which dynamic definitions can be practiced, barriers which exclude and marginalise can be challenged, and the nature of difference can be explored encompassing identity and diversity.

Conclusion

This paper has presented the Australian experience of disability through four themes – the denial of citizenship, segregation in institutions, living on the margins and the “disabled body.” Each of these themes represented an understanding of disability that was founded within a modern framework. Modern and post-modern frameworks and conceptualisations of disability were then contrasted, with an emphasis on themes that will enable understanding of disability, as well as studies, research and practice, to move forward.

Rachel Carling-Jenkins, Ph.D., is a part time Research Fellow at Monash University, Australia and has a son with Asperger’s Syndrome.

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End Notes

¹Hegemony represents the projection of a world view which permeates the social consciousness and becomes accepted within society as common sense.

²A meta narrative is a story (narrative) that provides a generalised, unifying explanation of the structure of society, including the justification of power structures within society.

Holier than Thou: Stigma and the Kokuas of the Kalaupapa Settlement
Akira Oakaokalani Ruddle-Miyamoto
University of Hawai‘i, Mānoa
Ron Amundson
University of Hawai‘i, Hilo

Abstract: This paper examines the intimate connection between stigmatization and concepts of race surrounding leprosy in 19th century Hawaii. This connection is revealed by consideration of the contrasting treatment of Father Damien and Native Hawaiian kokuas at the Moloka‘i settlement in the Western media. Demonstrating how prevailing prejudices affect stigmatization.

Key Words: Damien, leprosy, Hansen’s Disease, Moloka’i, kokuas, Kalaupapa, stigmatization

“In 1866 the first group of Hansen’s Disease Patients was forced into isolation at Kalaupapa to prevent the spread of leprosy. It was the humanity of Father Damien that brought hope to the Settlement, where he lived and worked with the people from 1873 until his death in 1889”
(Text from a Kalaupapa National Historic Park Remembrance Pin).

Introduction

In 1865 King Kamehameha III signed the Act to Prevent the Spread of Leprosy at the urging of the Western dominated Board of Health of the nation of Hawaii. This Act criminalized leprosy. It allowed for the arrest and detainment of people suspected of having leprosy and the exile of people diagnosed with the disease to an isolated peninsula on Moloka‘i called Makanalua. A settlement was established on the peninsula at the village of Kalaupapa and is today know as the Kalaupapa National Historic Park. The overwhelming majority of those who contracted leprosy in the 19th century in Hawaii were those who lacked immunity to the disease, those whose ancestors did not have the historical experience with leprosy to mount an immunological defense. In 19th century Hawaii, those who were especially vulnerable were Native Hawaiians. Therefore the overwhelming majority of those exiled to Kalaupapa were Native Hawaiians. Native Hawaiians resisted this law. They concealed and protected family members with the disease. Native police officers would often refuse to arrest “leprosy suspects,” so Western officers were assigned the task. When an arrested patient was declared incurable and exiled to Kalaupapa, a single family member or friend was allowed to accompany the exiled person. These individuals were known as kokua, a term which also means “to give help” in Hawaiian. Kokuas had always been a part of the Hawaiian culture. When help is needed, it is given. At Kalaupapa they served as nurses, housekeepers, farmers -- providing for their loved ones who could no longer provide for themselves.

The stigma of leprosy is as much a part of the disease as are the physiological symptoms. Leprosy would not be leprosy without the stigma of “loathsomeness” which surrounds it; as we will see, this stigma is literally more contagious than the disease itself. However the idea of leprosy’s loathsomeness comes from the Western experience of the disease. Native Hawaiians did not find leprosy particularly loathsome. Western reports from the period abound with sensationalistic descriptions of the Native Hawaiians’ apparent lack of disgust towards leprosy and those who had contracted it. Kokuas specifically, and Native Hawaiians in general were

additionally stigmatized by Westerners for their reaction towards leprosy. The kokuas who provided a valuable service which would not have otherwise been provided were stigmatized in the Western media, sometimes described as even more loathsome than the leprosy patients themselves (native Hawaiians who contracted leprosy were often thought to be sinful, but those who did not shun them were worse). As inhumane as the Western community's treatment of the kokuas may be, it is consistent with the prevailing Western attitudes towards leprosy and Native Hawaiians. If every person who traveled to Moloka'i to aid the exiled leprosy patients were stigmatized in the same way as the Native Hawaiian kokuas, there would be no topic for this paper. However there is a glaring inconsistency between the treatment of kokuas generally and the most famous of Kalaupapa's residents, Father Damien—an inconsistency made all the more apparent by his recent election to sainthood ("Father Damien," 2010). Existing Western prejudices allowed Father Damien to (or perhaps necessitated that Father Damien) escape the stigma of loathsomeness associated with leprosy and the stigma of that was attached to the Native Hawaiians who did not shun those who contracted the disease.

Ohana Tradition

In Native Hawaiian culture the family or 'ohana is of central importance. Handy and Pukui comment on the centrality of 'ohana in discussing the family system of Ka'u. "The fundamental unit of social organization of the Hawaiians of Ka'u was the dispersed community of 'ohana, of relatives by blood, marriage and adoption...tied by ancestry, birth and sentiment to a particular locality which was termed 'aina'" (1972, p. 2). According to Native Hawaiian mythology one was linked to the land through familial ties. This feature of Hawaiian culture explains why the 1865 leprosy law was so devastating to the culture. The enforced exile of the lay not only separated people from their families but also the land or 'aina, the "particular locality" to which they belonged.

The importance of the 'ohana tradition is not merely spiritual, it is also practical. The 'ohana provided for the needs of each member, if one could not care for themselves they could rely on their 'ohana to kokua, or help out. In the old days (and in many ways this tradition, or custom, or sentiment, regarding the importance of family still exists in contemporary island life) one's 'ohana was always there in times of need. Samuel Kamakau was a Hawaiian historian of the 19th century, and one of our best connections to indigenous customs. He movingly describes the kokua tradition, "The wife nursed the husband or the husband the wife, and when the children fell ill the parents nursed them" (quoted in Inglis 2005, p. 213).

To Native Hawaiians, leprosy in and of itself was not horrifying, as it was to most Westerners. What differentiated leprosy from other diseases for Native Hawaiians was the severe policy of exile. Native Hawaiians were not horrified of leprosy because of the special stigma associated with it, nor the physical symptoms of the disease, or even because of the functional loss which occurs as the disease runs its course. All of these would be mitigated by the support of one's 'ohana. But the Western system of exile meant separation from that 'ohana, and this truly was horrifying. As historian Kerri Inglis states, "Significantly Hawaiians did not name the disease for what it did to their bodies but for what it did to their 'ohana': they called it mai ho'oka'awale, meaning the separating sickness" (2004, p. 10).

When Queen's Hospital opened at a temporary facility at the corner of Fork and King Streets "...the staff had no nurses. Instead family members, relatives, or friends cared for the patients...In fact, the first trained nurse at Queen's, Mrs. Mary Adams, was not hired until 1886"—a full thirty-seven years after it opened (Kanahele 1999, p. 103)! For nearly four decades Queen's hospital was staffed by volunteer kokuas. It is important to note that there are no Western reports concerning the loathsomeness of the kokuas at Queen's. The loathsome status of Native Hawaiian kokuas is predicated on the especially loathsome disease of leprosy which affected those they cared for.

Again, although leprosy held special horror for Westerners, Native Hawaiians did not share the same views. To Native Hawaiians leprosy was simply the latest disease of many to afflict them. Several earlier epidemics had swept the community. Smallpox, measles, syphilis, influenza, and a disease thought to be cholera each had devastating effects prior to the discovery of leprosy. When Captain Cook made the first European contact with the islands he estimated the population at 400,000, although later estimates go to 800,000 or more (Stannard, 1989). The first official census in 1832 gave a population of about 130,000. By the 1850 census the native population had dropped to 84,000. In 1900 there were about 28,000 native Hawaiians and 8,000 part Hawaiians. It is still not fully known what caused the tragic drop in population, but the effects of Western diseases on people who had no hereditary immunity was one significant cause (as it was in other colonized populations including Native Americans).

Contrasting Views

The Native Hawaiian response to leprosy was no different from their response to any other disease. Family members cared for the sick. Family members who had not contracted leprosy would accompany loved ones who were exiled to Kalaupapa when permitted. Western reports from the period clearly indicate that Native Hawaiians did not discriminate against people with leprosy at all, "They [Native Hawaiians] surround smallpox sufferers and kiss, embrace and sleep with lepers without any suspicion of results" (Hagan, 1886, p. 88). George Woods writes that, "the developed leper, in all his ugliness, deformity and corruption, is in no wise treated differently from the native brother, clean and free from all imperfections, but is permitted to share house, food, clothing, bed and pipe; to intermarry with uninfected, and beget children—no relation of life being denied to him" (1887, pp. 5-6). From William Bliss we learn that, "...the natives are heedless of the danger which threatens them from association and contact with it [leprosy]. Rather than allow their leper relatives to be taken away, they secret them from searching officers by hiding them in the valleys and cane-fields" (Bliss, 1873, p. 92). We will term this secondary stigma the "non-disgust" stigma. In it, two significant Western biases shine through, one, the patronizing tone of the Western authors, clearly indicates that they viewed the native Hawaiian response to disease as absurd, and two, the use of such language as, "heedless of the danger," or "without any suspicion of results," to describe the Native Hawaiian response clearly indicates that the Western authors did not believe that Native Hawaiians knew well enough to be disgusted with leprosy or disease in general.

However, Native Hawaiians recognized various types of illnesses including infectious diseases, hereditary diseases and even hereditary predispositions towards particular diseases. An illness might also be sent by the 'amakua, ancestral gods, as punishment "... for doing evil,

breaking oaths, and wrong doing against consecrated things...and all sorts of other errors.” Remedies ranged from prayers and sacrifices to the ‘amakua, to medicine, depending on the type of disease. Medicine was not used to treat diseases that were sent as punishment by the ‘amakua “...lest the force (mana) of the medicine cause his [the patients] death” (Kamakau, 1993, p. 95). Sacrifices were made to the ‘amakua, this “...was the work of the family, it could not be done by outsiders or strangers because their voices and appeals would not be heeded by the ‘amakua” (Kamakau, 1993, p. 97). Hawaiian Kahuna, a specific class of priests, “...were skilled in examining newborn babies and their parents to discover signs of pa‘ao‘ao. Pa‘ao‘ao ailments (ma ‘i pa‘ao‘ao) cling to (pili pu) the parents. When their children are born, they pass on (pili aku) the pa‘ao‘ao, as well as physical disabilities (ma ‘i lolo) and inherited diseases (ma ‘i ku‘una)”, as well as looking for signs of ‘ea “widespread” illnesses (Kamakau, 1993, p. 101). Kamakau interprets pa‘ao‘ao and ‘ea as medical classifications that include predispositions to diseases as well as the diseases themselves. His examples indicate that pa‘ao‘ao was a classification for malfunctioning of the body and ‘ea a classification for diseases that are now recognized as infectious (1993, p. 114, endnote 5).

It is clear that the ancient Hawaiians possessed complex theories of disease causation. In addition it should be recognized that leprosy has a very complex mode of contagion. Most people (even among the Native Hawaiians) are naturally immune to it, and it can take up to thirty years to develop. So even the best Western authorities were unsure that it actually *was* a contagious disease – it might equally well be caused by heredity, sanitation, or food custom (raw fish was under suspicion by Western specialists). Hawaiians apparently did not believe in the contagiousness of leprosy, but most Western specialists didn’t either. So the Native Hawaiian non-disgust of leprosy was not due ignorance of disease causation or lack of a theory of contagion.

Hawaiians simply did not stigmatize diseases in the same way as the West. They did not stigmatize leprosy because of its physical effects. This was a striking difference between the two groups. Westerners, apparently universally, had a reaction of disgust to the symptoms of leprosy, and Hawaiians did not. Westerners shunned and segregated those with leprosy. Hawaiians did not. Healthy members of an ‘ohana would care for sick members, just as they always had, and showed no reluctance to touch or to share food with people with the disease. Many Western commentators remarked on this. Some claimed that Hawaiians were unique in world for failing to react with disgust to the symptoms of leprosy, and many asserted that Hawaiian lack of disgust was innate to their “race” (A Hawaiian Government School Teacher, 1897-1898; Bliss, 1873; Gibson, 1873; “The Hawaiian leper colony,” 1894; Mouritz, 1916; Musick, 1898; Woods, 1887). (This concept is discussed further in Amundson & Ruddle-Miyamoto, in press.)

It would be naïve to believe that the Westerner belief in contagion was the cause of the Western perceptual reaction of disgust. The Western stigmatization of leprosy occurred in an atmosphere of medical ignorance and controversy about the cause of the disease. A contagion theorist might have an easier time justifying segregation out of fear of an epidemic, than a heredity theorist, a nutrition theorist, or a sanitation theorist, but each kind of theorist can find a way to justify segregation, and they did (Pandya, 1998; Sato & Frantz, 2005). Hawaiians did not.

Unfortunately for Native Hawaiians, because leprosy did hold special horror to Westerners, and because foreign influence in the islands was growing, and because the white men were already convinced of their own superiority and therefore the correctness of their views and their ways, those who did not shun people with leprosy were shunned themselves. Those who did not stigmatize those with leprosy, those who did not share the “wholesome horror” of the Westerners were stigmatized for their *failure* to stigmatize. (“Wholesome horror” was Woods’s apt term for the disgust instinct, which he considered innate to Western minds [1887, p. 8]) By failing to be disgusted by leprosy Native Hawaiians proved their inferiority. Their susceptibility to disease and their un-Western (i.e. unenlightened or uncivilized or immoral) ways of dealing with disease were often spun into paternalistic arguments by foreigners and used to delegitimize the Native Hawaiian sovereignty. The Moloka‘i kokuas, and Native Hawaiians in general, were viciously stigmatized for their willingness to associate with and care for those with leprosy. Native Hawaiians, especially the kokua who accompanied patients to Kalaupapa, were portrayed by Westerners as lazy natives anxious to contract leprosy in order to live off the government. For example, Musick comments casually:

“...And some of the natives, I have been told, are anxious to be declared lepers and sent to Molokai, where they will be supported at the expense of the government”. Bliss informs his readers that, “This support [government rations] is so much better than any Hawaiian ever has at home, that natives living on other parts of the island have desired to make themselves lepers in order to be taken care of in this village of death” (1898, p. 93).

The Western reaction to the Hawaiian non-disgust with the symptoms of leprosy was a distinct stigma, separate from “loathsomeness” of leprosy itself. The superiority of Western disgust over native non-disgust was a factor in the belief in Western supremacy over native groups, as Shankar points out (2007). We will use an example to demonstrate the material significance of this stigma. It was not merely a matter of the social reputation of Hawaiians. It was a potential cause of death. Our example is the research of Dr. A. A. Mouritz.

Mouritz’s Story

Among the most extravagant applications of the stigma of non-disgust attributed to Hawaiians is the claim that many Hawaiians actually desired to have leprosy in order that they might take advantage of the free living provided by the government at the Moloka‘i settlement. These allegations combined the attributions of non-disgust with what looked (to Westerners) like Hawaiian fatalism regarding diseases. Most of these claims are apparent fabrications, made by travelers (such as Musick and Bliss) whose information seems to have come from local Westerners, not from Native Hawaiians themselves who actually did wish to have the disease. The motive for spreading these rumors is pretty clearly to defend the generosity of the government program of segregation. The allegation was that the government was so generous to the exiles, and Hawaiians are so indolent, that many of them would rather have leprosy and live off the government than work for a living. Coming third-hand from travelers who spoke only with local Westerners, and contradicting the voluminous records of Hawaiian resistance to the exile laws, these claims have little weight.

However, one set of assertions comes from first-hand knowledge. It is the following claim made by Dr. A. A. Mouritz, physician to the settlement on Moloka‘i from 1884 to 1887. Mouritz reports not the desires of non-exiles to become exiles, but the desires of the kokuas that already lived in the Moloka‘i settlement to actually acquire leprosy themselves:

“In order to lead a lazy, free from care existence, many kokuas, or helpers, are willing to become lepers at the Molokai Reservation; try to imitate the signs for leprosy by burning their skins, rubbing in irritating substances, and by other traumatic means, desire to be placed on the list as lepers in order to get their daily food free” (1916, p. 3).

Given the extravagance of this claim, we must ask whether Mouritz himself is a good source of information on the behavior of the kokuas. He was in direct contact with them during the three years he was the physician at the Moloka‘i settlement. But is he a disinterested observer? Decidedly not. Mouritz had an extremely strong reason to lie about these facts. He had performed highly unethical medical experiments on the Moloka‘i kokuas by attempting to inoculate them with leprosy. Only by alleging that the kokuas actually *wanted* to be infected with leprosy in order to get free handouts, could Mouritz defend himself against the charge of medical malpractice. Let us examine Mouritz’s behavior regarding the kokuas.

During the early years of the settlement, kokuas had been allowed to draw rations along with the exiles. It was recognized, after all, that the settlement simply could not run without the kokuas. But as the size and the expense of the settlement increased, the Board of Health wanted to reduce the costs. In 1873 the kokuas were forbidden from receiving rations (Tayman, 2006). When Mouritz arrived in 1884, he reported to the Board of Health that some kokuas had been falsely diagnosed with leprosy and allowed on the rations list. He promptly threw them off (Mouritz, 1916). Some of the kokuas (like some of the exiles themselves) could find ways of making a living at the settlement. But the basic source of food for many of them was the meager rations given to the exiles. (The Board of Health declared that the rations were only for the exiles. But the ridiculous notion that exiles should not share their food with their kokuas was of course ignored.) Some kokuas acquired leprosy (Mouritz estimated 9.2% per year) and were put on the rations list. The rations list remained the primary resource for food, clothing, and other supplies in the settlement, and there was a strong motivation (namely hunger) for other kokuas to find a way to get on it. The only way to get on it was to convince Dr. Mouritz that one had leprosy. This is the context in which we must view Mouritz’s behavior towards the kokuas.

Mouritz’s 1916 book *The Path of the Destroyer* argues that leprosy enters the body via the alimentary canal, and that it cannot be inoculated. The fact that leprosy cannot be inoculated tends to exonerate Mouritz from his earlier criminal acts--he had attempted on hundreds of occasions to inoculate with leprosy a person who did not have the disease. These were the kokuas that he referred to as wanting a “lazy, free from care existence.” Mouritz, like other Westerners, was surprised that the kokuas were not disgusted by the stigmas of leprosy, and had voluntarily accompanied their family members into exile (rather than shunning them, as was expected by Westerners). They seemed to have no fear of the disease, an attitude that Mouritz described as stoic and fatalistic. Now he found that many of the kokuas claimed that they themselves had leprosy. Mouritz seems to have interpreted this to mean that they genuinely desired themselves to have leprosy, not that they honestly believed themselves already to have

leprosy. In some cases he may have been right; we can never know. However, we do know that Mouritz exploited the situation by attempting to give the kokuas leprosy by inoculating them with “serum” that he derived from the bodily lesions of people who genuinely did have leprosy. Mouritz may well have believed that these results would advance his reputation as a medical researcher. One of his predecessors, Dr. Edward Arning, had advanced his international reputation based on research done at the Moloka‘i settlement by inoculating with leprosy a convicted murderer named Keanu in 1884 (Mouritz, 1916, p. 154). Keanu volunteered for the experiment under the inducement of avoiding his sentence of hanging, and Arning received considerable attention for his act. The outcome of this “experiment” was ambiguous (Keanu developed the disease but was discovered to have lived for years with relatives who had leprosy anyway) and Arning was heavily criticized for his behavior (as we shall see). However, Mouritz did not know of these outcomes at the time he inoculated the kokuas; he only knew that Arning had received international attention. Mouritz may well have expected the same kind of attention from his experiments.

Because we have only Mouritz’s reports on these potentially lethal experiments, we cannot be certain of the exact degree of deceit and intimidation involved in them. Mouritz had the authority to put these people on the ration lists or to remove them. As the settlement’s physician, it was he who “convicted” people of leprosy. How hungry were the kokuas? How hard was it to get food by other means than the ration list? How serious were the kokuas in their professed beliefs that they already had leprosy? We have only Mouritz’s word about this matter. However, Mouritz was deliberate in describing the 15 kokuas (10 men and 5 women) who were subjected to his repeated experimentation. Most of them are described in disparaging and racially charged terms. His general description of the group indicates that they were:

“Healthy kokuas, all ready and willing to be experimented on by inoculation, serums, or any other means likely to develop leprosy; the artificially made lepers hoping to obtain board and lodging, for the remainder of their lives; being listed as lepers -- a livelihood and existence without working being provided by the Board of Health. What other country of the world save in Hawaii, would people be found willing to take the chances of acquiring a loathsome and incurable disease? The sole object to be gained for the loss of health and shortened lives, *being maintained at public expense*” (Mouritz, 1916, p. 140, emphasis in original).

However, when we get down to details, the truth of these assertions is highly doubtful. Mouritz is quite confident that he knows when the patients are lying about believing themselves to have leprosy, and this is one point at which we might doubt his claims. The matter becomes even murkier when we see the grounds on which Mouritz offers to “treat” his experimental subjects. The very first patient (referred to as “A”) asserts that he has leprosy and wants to be put on the ration list. Mouritz reports that he “taxed” the patient with causing his own skin sores, and the patient denied it. Now, does Mouritz offer to inoculate the patient with leprosy? No. Here is his description of what he told the patient: “I informed ‘A’ I would use certain measures to decide his case. He specially stipulated his non-desire for hypodermic treatment, but agreed to submit to any other medicines I might see fit to use.” Mouritz went on to inoculate “A” with “leprous serum from burn vesicles [blisters caused by burns] ... rich in bacilli leprae” (Mouritz, 1916, pp. 141-142).

Note that Mouritz did not tell the patient that he was going to inoculate him with leprosy. He offered to “use certain measures to decide his case.” Then he inoculated him with leprosy. Was the patient aware that he did not already have leprosy, but that the physician was trying to give him leprosy? We do not know and Mouritz does not tell us. Mouritz believes that the patient wants to have leprosy, and this is his justification for treating the patient as he does--as something less than an autonomous decision maker.

This procedure is similar with many other patients. The inoculations are described to the kokua not as attempts to cause leprosy in them, but to determine whether or not they already have leprosy, with the possible award of being put on the rations list. In the case of patient “D” Mouritz says that “to refute his claim of being a leper, I inoculated four foci with leprosy serum in the month of December, 1885” (1916, p. 143). Several of the kokuas are described as “desirous of having leprosy,” but many others are merely described as claiming that they did have leprosy, and of claiming it in order to get on the ration list. The notion that inoculation with leprosy is a way to “refute” a claim of leprosy (case “D”) or a way to “decide the case” of leprosy (case “A”) is a blatant lie, told to an experimental subject, about the purpose of an experiment. The procedures were described to the subjects as tests to ascertain whether the subject had leprosy. But they were actually attempts to give the subject leprosy. Mouritz’s excuse for this behavior was that the kokuas all wished that they had leprosy anyhow. The non-disgust stigma, together perhaps with what Mouritz called stoicism or fatalism, earned these people an inoculation with leprosy.

Mouritz’s report of his experiments is told in a jolly manner, made possible because he knows in 1916 that all of the attempts to inoculate with leprosy failed, and indeed must have failed because leprosy is not inoculable. However, that is not the way we determine guilt. Consider William Tebb’s assessment of Dr. Arning’s inoculation of the criminal Keanu with leprosy as a way to avoid hanging. It was described as “a punishment ten times more severe than the death penalty, and, in my judgment, entirely unjustified” (Tebb, 1893, p. 125) (This description also illustrates the very high stigma attached by Westerners to leprosy itself – the possibility of future leprosy was worse than immediate hanging!) The more relevant question regarding Mouritz’s own guilt is not whether his inoculations were successful, but whether he had believed that they would be. With his hindsight in 1916, he knew that they couldn’t. But in 1886, as we know from his own report to the Board of Health, he believed that those experiments probably would produce leprosy in their subjects. He had told the Board “I believe that the ‘contagium’ of leprosy enters the system by: 1) inoculation a) at broken surfaces of the skin, b) at broken surfaces ... on external mucous surfaces, c) possibly by puncture by insects ...” (Mouritz, 1916, p. 378). So when he inoculated those kokuas between 1884 and 1887, he fully believed that he was causing their death. He was doing so, at least in many of the cases, without the kokuas’ knowledge. What justified this act in Mouritz’s mind was something about the nature of the kokuas’ beliefs and attitudes. They were indolent, undisgusted by leprosy, and cared little about their lives. The medical ethics of a Western doctor were easily bent to fit such a case. He reported that “... stretching all questions of professional ethics, I did not hesitate to avail myself of the opportunities afforded me for testing the inoculability of leprosy. My chief regret is that I have so little to offer in results obtained on this much debated question” (Mouritz, 1916, p. 141). Dr. Mouritz should regret much more—malpractice, if not attempted manslaughter.

R. D. K. Herman notes that the nature of “the Hawaiian” was described differently by Western authors at different times, the descriptions varying to suit the needs of the various stages of Western colonization (1999, p. 409 ff). Hawaiians were *diligent workers* when capital needed to be raised, they were *indolent* when the importation of foreign workers was needed to aid the sugar plantations, and they were *welcoming* when the tourism industry needed to attract visitors. Here we see a very specialized example of such description. Mouritz desires to have *voluntary* subjects for medical experimentation. The non-disgust stigma combined with Hawaiians’ alleged fatalism about disease implied, to Mouritz, that the kokuas were perfectly suited for such experimentation.

Enter Father Damien

Enter Father Damien. There are several ways in which Father Damien differs from the Native Hawaiian kokua. Father Damien was not a close friend or family member to anyone at the settlement. Father Damien was not Hawaiian and therefore was not influenced by the ‘ohana tradition but rather Christian ethics, perhaps even Western paternalism. Whatever his reasons, Father Damien was a volunteer who cared for people who lived with leprosy just like the Native Hawaiian kokuas at Kalaupapa and elsewhere. It is in this willingness in not letting the stigma associated with leprosy stop him from giving his help – his kokua – to other human beings that he is exactly like the kokuas of Kalaupapa. The question at hand is, given that Father Damien was praised for his actions and his willingness to associate and care for those with leprosy, why were the Native Hawaiians stigmatized for the very same behavior? To understand the difference in treatment, and to locate its cause, we must take a closer look at the ways in which Damien did differ from the Native Hawaiian kokuas.

Scientific racism, as it existed in the 19th century, was very different from beliefs about race as they exist today (even among today’s racists). The scientific authorities of the day did not distinguish between the biological and cultural attributes of different races – all differences were “racial.” The modern concept of *culture* (as variations in tradition and beliefs between groups of people) was absent (Stocking, 1994). If a belief, a behavior, or a mode of thought was widespread in a “race” of people, it was regarded as ‘racial,’ and fixed by biology. The ‘culture idea’ (which legitimated the scientific opposition to racism) slowly became a part of modern thought because of the growing influences during the early 20th century of cultural anthropologists like Franz Boas, some broadminded biologists, and eventually a recognition of the eugenic horrors of World War II (Barkan 1992; Provine 1986). Scientific racism in the 19th century presumed that Western civilization was based on *rationality*, the highest attribute of humanity. Reason is said to be the essence of human beings. Since reason establishes moral society, or civilization, civilization can be used as a measure of rationality, and since “civilization” is moral society, civilization can also be used to measure morality. The more advanced your civilization the more rational and the more moral you are. Therefore the more closely a society resembles Western civilization the more rational and moral they are thought to be. The more human one is, the more superior one is relative to the “lower” or less rational animals. The white man stands *contra mundo*, against the world, distinct from all non-Western groups since those groups lack Western civilization (Barkan, 1992). Some groups may come closer than others, they may even be admirable (Native Americans were often used as an

example of the “noble savage” in the racist literature of the 19th century), but ultimately all are inferior to Western civilization. Historian Sonia M. Lee describes the racist attitude held by Westerners of the colonial period: they held “the belief in the cultural and moral superiority of the white race, which bore the burden of civilizing and saving the world” (2000, p. 178).

The question comes to mind: What made Westerners so confident of their superiority? One fact marks Western civilization as superior, irrespective of the variation in beliefs about rationality and morality. It is Western military might, from the sixteenth through the nineteenth centuries, when the West was conquering and colonizing other cultures. This is the single objectively determinable fact that does not first require some moral presupposition to be labeled as superior. They conquered, thus they were de facto militarily superior. But remember that this is “superior” in a very limited sense—superior military strength. Superiority is manifest by conquest, by successfully exerting your will on the world. There is no doubt that the slogan *might makes right*, an idea which makes conquest good, is a Western idea (though perhaps not uniquely Western). During the colonial period, the very fact of success in conquest was used to justify expeditions of conquest. The evolutionary slogan “survival of the fittest” was superimposed on military conquest; success in war was seen as a law of nature, and the “fitness” to rule was demonstrated by the military ability to conquer. Or, in the case of Hawaii, the ability to convince the local authorities (the royalty) to comply with the desires of powerful Western visitors and immigrants. The superiority of Western ways of life (and Western individuals) was shown by their dominance.

This perspective, or one very much like it, was present and operating in the minds of most Westerners in the islands from the time of Cook’s arrival, throughout the 19th century, and perhaps even today. This conception of the superiority of Western moral or intellectual traits frames the way in which Westerners perceive non-Western peoples. Native Hawaiians, as members of a lower race, are inherently inferior in their beliefs and desires. In first half of the 19th century their behavior was described by early missionaries as impure, unclean, immoral, sinful, indolent (an especially popular description), and loathsome (especially in traits that were believed to bring on disease, like domestic arrangements and eating raw fish). These traits, for many Western observers, explained why Native Hawaiians more than any other group were struck by that most loathsome of diseases, leprosy. Herman writes that, “The introduction of diseases by foreigners was portrayed as only a contributing factor to an inherent spiritual and physical deficiency in the Hawaiian peoples – ‘Their very blood is corrupted and the springs of life tainted with disease’”. Herman goes on to report that “[Native Hawaiian] behaviour was said to compound the problem: they ‘hold life at a cheap rate’, ‘take little care of themselves’, live in houses ‘small, filthy, and open to the rain’, and are ‘exceedingly slovenly in their habitations and persons’. All of this was said to ‘show but too plainly the intimate connection between sin and suffering’” (Herman, 2001, p. 322, quoting letters published in the mission journal *Missionary Herald* published during the 1820s and 1830s). On this conception, Native Hawaiians brought diseases upon themselves. This too could be considered a ‘natural’ process. Aware of the drastic reductions in many colonized populations and the immense health problems of African Americans under slavery, many authorities believed that non-white races were gradually going extinct due to their inability to thrive under ‘civilization.’

As a Westerner, Father Damien is assumed to be morally superior. He understands

leprosy and recognizes its loathsomeness. As members of a backward race, Native Hawaiians did not know well enough to shun those with leprosy (the healthy Hawaiian being just as sinful and indolent), and so can be blamed for contracting the disease. In addition their actions -- caring for those who had contracted leprosy or any other disease for that matter -- are the result of ignorance, not compassion, devotion, charity, or love. They inherently lack rationality and rational morality. Therefore their willingness to care for those with leprosy is not an act of selflessness, but rather ignorance. Any rational person is disgusted with leprosy, and therefore the Hawaiians' actions are not praiseworthy, but condemnable as base. Father Damien, on the other hand, as a member of an enlightened (*the* enlightened) race, knows full well the "sinful" nature of leprosy, its loathsomeness, and the risks of contracting the disease himself. But he has managed to overcome his disgust (in the disease itself, and the immoral wretches who have contracted it) and so he can be revered as a paragon of the ideals of selflessness and compassion. Damien's actions are praised as supererogatory and when those very same actions are performed by Native Hawaiians they are said to be base -- the difference is not in the action but the actor. (The difference cannot be that Damien was Christian, because by this time many Hawaiians had converted to Christianity.) Since Damien is informed, educated, intelligent, and moral his decisions are rational and his actions can be praised as selfless, while Hawaiians can be condemned for selfishness or greed for doing the very same thing. And so we realize that of all the aforementioned differences the most significant is that Father Damien was not Hawaiian, he was a white man.

Conclusion

At first it appears that there is a double standard at work in the stigmatizing descriptions the Western press published of the Hawaiian *kokuas* and of Father Damien. But this inconsistent treatment is completely in line with the prevalent conceptions of racial difference and Western superiority. In fact, such conceptions necessitate this inconsistent treatment. To stigmatize Father Damien for his willingness to touch and care for the "loathsome" exiles would be tantamount to admitting that Westerners are, or at least can be, just as "indolent" as the Native Hawaiians. It would undermine the idea of Western moral superiority. Damien must be made into a saint and Native Hawaiian *kokuas* must be demonized, or at the very least to have their loyalty, selflessness, and bravery overlooked. Although Native Hawaiian *kokuas* performed the same actions as Damien, they were said to be motivated by ignorance, indolence, or a combination of the two. If Native Hawaiians were capable of the same compassion, the same selfless motives as the Belgian Priest, then they are just as moral, and if this is so, then the white man is just as base.

Akira Oakaokalani Ruddle-Miyamoto is currently pursuing a Masters in political theory in the Department of Political Science at the University of Hawaii at Manoa. His focus is the political philosophy of Thomas Hobbes. He formerly was Professor Amundson's undergraduate research assistant.

Ron Amundson is Professor of Philosophy at the University of Hawaii at Hilo and specializes in the history and philosophy of biology and disability studies. He currently studies how theories in evolutionary biology affect our understanding of human variability, including the nature of disability.

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Family Bookmaking: An Approach to Support Parent-Child Language Interactions in Natural Environments

Lisa K. Boyce, Ph.D.; Mark S. Innocenti, Ph.D.; Lori A. Roggman, Ph.D.; Cora Price, B.A.;
Vonda K. Jump, Ph.D.; Gina Cook, M.S., & Eduardo Ortiz, Ph.D.
Utah State University, USA

Abstract: This study examined the effectiveness of family bookmaking to promote early language development. Forty-two children receiving early intervention services and their families participated in the study. Our results suggest that family bookmaking engages parents, increases the quality of parent-child language interactions, and increases children's understanding of language.

Key Words: bookmaking, language, family, early intervention, exploratory, children

Introduction

Home visiting to families with young children is a long-standing means of delivering services. There have been a number of reviews and meta-analyses that report positive effects of home visiting (Daro, 2006; Sweet & Applebaum, 2004). However, the research on home visiting has been criticized because the term describes a place for delivering services rather than a description of the service delivery model being used (Chaffin, 2004; Gomby, 2005). This critique is relevant to the field of early intervention for young children with disabilities (Part C). A recent report to Congress reported that 80.7% of all Part C children received their services at home (U.S. Department of Education, 2009), but service delivery models within the home have not been well described.

This does not imply that service delivery models have been ignored. There has been an active discussion of what constitutes early intervention home visiting best practices. Baird and Peterson (1997), more than a decade ago, urged a shift from *practitioner-directed intervention* towards an *emphasis on parent-child interaction and family-directed* early intervention experiences. They argued that parents could and should become more informed decision makers and be proactive in their children's development. Bailey and colleagues argued that for intervention to be effective in facilitating children's development, practitioners need to address parent-child interactions in the environments where children live (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). A workgroup of experts in the field of early intervention recently came up with *recommendations* that support this focus on *parent-child interactions*. The Workgroup on Principles and Practices in Natural Environments (2007) identified seven best practice principles based on current research and clinical evidence that emphasize the importance of the family, the parent-child relationship, and the use of everyday environments to facilitate learning.

Despite this emphasis, research has found that those providing home visits do not implement recommended practices (Campbell & Sawyer, 2007; McBride & Peterson, 1997; Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007). Even more of a concern was a recent study that surveyed 241 multiple-discipline early intervention practitioners and asked them to describe

“three wishes” they would make to change early intervention (Campbell & Halbert, 2002). Practitioner responses uniformly conflicted with recommended early intervention best practices, including family-centered intervention and provision of services in natural environments. The findings from this research indicate a disconnect between what practitioners believe or do, and practices derived from and supported by research (e.g., Dunst, Trivette, & Hamby, 2006; Kim & Mahoney, 2004; Mahoney & Wiggers, 2007) and federal program guidelines.

It is impossible to say from this research why early intervention practitioners are not implementing recommended practices. Perhaps one reason is that recommended practices do not immediately lead to clear and specific strategies that can be implemented by a practitioner. If this were a reason, then strategies that provided a concrete way to help practitioners engage parents in developmentally supportive interactions with their children would help improve practices. The current study examines one approach, consistent with recommended practices, for providing practitioners a more structured approach to support parents’ facilitation of their children’s early language development.

Practitioner encouragement of parent-child interactions that support children’s development may be particularly salient for promoting social-emotional, cognitive, and language development. With such an approach, the practitioner helps parents identify and enjoy activities with their children that promote development, guides parents to identify and interpret cues and attempts at communication, and encourages parents to be responsive to their children’s needs, interests, and emerging skills (Roggman, Boyce, & Innocenti, 2008). Early intervention providers have been encouraged to shift to this type of parenting-focused approach where they move from working directly with a child to providing coaching for parents to facilitate their child’s development (Mahoney & Wiggers, 2007). The encouragement of parental responsiveness and developmental support seems to be especially important in language and literacy activities. Indeed, the quality of parent-child interactions during literacy activities, such as encouragement, motivation, and socioemotional support, may be more important to children’s language and emergent literacy skills than mothers’ beliefs and practices for children with language impairments (Skibbe, Justice, Zucker, & McGinty, 2008). In addition, even though research suggests that delayed children are not as engaged in play interactions as typically developing children, maternal responsiveness has been shown to be a better predictor of child engagement during play than disability status (Kim & Mahoney, 2004). Promoting maternal responsiveness, particularly in enjoyable language interactions, may be a critical part of early intervention services for children with language delays. This study focuses on the evaluation of such an approach. We collaborated with two different Part C early intervention programs to develop a family-centered approach that builds on recommended practices and previous research to promote children’s development.

Intervention

Consistent with research findings (Peterson et al., 2007), our observations of early intervention home visits were that early intervention practitioners usually worked directly with children with disabilities, “modeling” appropriate ways to elicit language. During this type of direct-services-modeling approach, families were often involved as observers and then as participants at the conclusion of the home visits when they were instructed how to continue to

work with their children to provide carry-over until the next home visit. In contrast, we developed a series of family bookmaking activities intended to engage the families in co-constructed narratives about everyday events to provide a context for meaningful, culturally appropriate, natural, and extended parent-child conversations. Using these narratives along with commonly available technology (digital printer and camera), families developed books that they could keep and continue to use. Within this structure, home visitors provided information on the importance of language and helped parents use specific strategies to encourage and extend children's language and communicative attempts during the narratives, bookmaking, and later book sharing. This type of approach was developed as a co-constructed, family-centered intervention.

The family bookmaking approach was designed to encourage ongoing language support and literacy activities through parent-child relationships in ways that would be individualized, flexible, engaging, and appropriate for all families. It is based on the research indicating that parent-child conversations, book sharing, and enjoyment are key to promoting children's language and emergent literacy. Specifically, a parent's labeling, describing, and explaining things related to a child's interests encourages that child's language development (Baumwell, Tamis-LeMonda, & Bornstein, 1997; Carpenter, Nagell, & Tomasello, 1998; Dunham & Dunham, 1995; Hart & Risley, 1995; Newland, Roggman, Boyce, & Cook, 1998; Pine, Lieven, & Rowland, 1997) as do parent-child conversations, storytelling, and shared narratives (Caravolas & Bruck, 1993; Hart & Risley, 1995; Hoff-Ginsberg, 1991; Melzi, 2000; Neuman, 1999; Whitehurst & Lonigan, 1998). Active book sharing interactions between parents and children support children's language and later literacy skills (Arnold & Whitehurst, 1994; DeTemple, 1999; Goldenberg 1994; Mason, 1992; Newland, Roggman, & Boyce, 2002; Valdez-Menchaca & Whitehurst, 1992). Parent-child enjoyment of these book sharing and other literacy experiences is also an important predictor of language and emergent literacy (Leseman & de Jong, 1998).

This approach was initially developed for use with low-income Latino families whose children were English Language Learners. However, this approach was adapted for families with young children with disabilities as a means to better meet the intent of family-centered practice and natural environments by providing a concrete way to engage family members in evidenced-based strategies that promote language development.

The process of family bookmaking is comprised of seven basic steps: (a) planning ahead with the family to encourage parent-generated ideas, with child participation, about book topics; (b) facilitating parent-child conversation, communication, and interest in the topic; (c) illustrating the story by taking and printing digital photographs; (d) helping the parent write captions from words, signs, gestures, or child interest in the parent-child narrative; (e) guiding the parent to involve the child in organizing and making the book; (f) supporting the parent and child reading and looking at the book; and (g) leaving the finished book for the family to keep.

A training process with accompanying materials to guide the intervention was provided to practitioners from our early intervention program partners. The training content included the theory of change, basic steps of family bookmaking, evidence-based strategies for parents to elicit language (referred to as the support-ask-expand (SAE) strategies), and methods the

practitioners could use to facilitate parents' use of the SAE strategies. A variety of book topic ideas were provided along with recommendations on using identified methods with different book themes. Information was provided on adapting book complexity and content to facilitate development and support IFSP goals. Specific examples were discussed for including developmental skills other than language and literacy, such as motor skills and social skills. As part of the training, practitioners tried the basic steps with a family not in the study, and these bookmaking experiences were discussed in subsequent meetings. Once home visits began, the trainers provided reflective supervision sessions (Roggman et al. 2008) to solve problems, address challenges, support strengths, and plan for future visits.

A formative evaluation that included a comparative study was conducted to examine the usability and feasibility of the family bookmaking activities. Several research questions were developed to guide the evaluation of this intervention.

1. Will early intervention providers and families experience these activities as meaningful, enjoyable, and effective in promoting language development?
2. Will parents participating in this intervention increase their use of language-supporting behaviors more than parents in a comparison group?
3. Will children participating in this intervention with their families score higher on parent reports of expressive and receptive language abilities than children in the comparison group?

Methods

Participants

Two-year-old children with disabilities and their families participated. These families were enrolled in two early intervention programs that were partners in our adaptation of this intervention. Families in these programs were assigned to the family bookmaking approach ($n = 21$) or a comparison group ($n = 21$). Children were selected for the study based on their birthdates, with target ages between 18 and 30 months. No children were excluded based on disability status, home language, or any other factor. Assignment to groups was based on the interventionist working with each family. The interventionist who worked with us on the development of the approach served as the primary interventionist for the children in the family bookmaking group. Comparison children were selected from the caseloads of other interventionists in these same programs. The study was conducted over seven months.

Table 1 provides information on key characteristics of the families in the two groups and the results of *t*-tests to examine group differences. Overall, children's ages at pretest ranged between 16 and 31 months ($M = 25.25$, $SD = 3.36$). Children had an average language delay of approximately eight months. Most families were Caucasian (85%) and most were married or living with someone. The average annual family income ranged from \$0 to \$105,000 ($M = \$35,750$, $SD = \$23,819$), and maternal education levels ranged from 4 to 17 years ($M = 13.55$, $SD = 2.33$). Raw maternal vocabulary scores ranged from 30 to 52 ($M = 42.20$, $SD = 5.60$). As shown in **Table 1**, mothers in the comparison group had statistically significantly higher education levels and raw vocabulary scores on the Woodcock-Munoz Language Survey than the

mothers in the family bookmaking group. Therefore, children in the family bookmaking group were particularly at risk for continuing language delays.

Measures

Assessments included maternal interviews and videotaped mother-child book sharing. Maternal interviews included demographic questions, child language questionnaires, and a maternal vocabulary assessment. Assessments were conducted before the intervention began and then again seven months later following the intervention. Assessors were trained to criterion on all measures prior to working with families. Assessments occurred in the families' homes, scheduled at their convenience.

Maternal expressive vocabulary was assessed only at pretest with the Woodcock-Muñoz Language Survey (WMLS). This measure was designed to assess language proficiency in either Spanish or English (appropriate norms are provided for both) and has a reported internal consistency reliability, using Cronbach's alpha, of .84 (Woodcock & Muñoz-Sandoval, 1993).

Child receptive and expressive language skills were assessed with the Receptive and Expressive Emergent Language Scale (REEL-3; Bzoch, League, & Brown, 2003) subtests. Results were obtained through a caregiver interview. The REEL-3 has a normative scale based on a normative sample of 1,112 infants and toddlers matched to the demographic characteristics of the 2000 census. The average reliability for the two subtests exceeds .90.

Parent-child book sharing behaviors were coded from a videotaped interaction of each mother and her child reading a book together for ten minutes. The book was a storybook with no words so that mothers of all literacy levels were able to participate. The oral narrative (spoken words) was coded for language supporting behaviors. Parent behaviors used to assist child language during the book sharing were tallied using a list of behavior categories (Whitehurst et al., 1988). Frequency counts were obtained of mother directives, labeling, reading/conversation, yes/no questions, simple what questions, imitative directives, praise, open-ended questions repetition, pointing requests, expansions, criticism, function questions, and other responses to vocalizations. In addition, child single word utterances or signs and multiple word utterances or signs were counted. Trained observers coded the videotaped interactions in 30-second intervals. At the end of each 30-second interval, coders stopped the videotape and recorded which behaviors occurred in the preceding interval. More than one behavior could be coded in each interval. For this evaluation, criteria for training and periodic agreement checks were .90 for simple agreement and .75 for agreement using the Kappa coefficient.

Parent satisfaction was assessed through an interview questionnaire that was developed to better understand how the intervention was received, what aspects were important to parents, and how the bookmaking visits affected families. Families who participated in the intervention completed the questionnaire in an interview format. Quantitative and qualitative satisfaction data were obtained. Qualitative responses were aggregated for each question for analysis, while mean scores were obtained for quantitative questions.

Early intervention provider satisfaction was assessed through an interview questionnaire

that was developed to better understand how the intervention was delivered, what aspects were important to providers, and how the bookmaking visits met IFSP goals and the needs of the children and families they served. Providers who participated in the intervention completed the questionnaire in an interview format. The interview was conducted by a research team member who had not worked directly with the practitioners. Quantitative and qualitative satisfaction data were obtained. Qualitative responses were aggregated for each question for analysis, while mean scores were obtained for quantitative questions.

Treatment Fidelity

Implementation fidelity is an essential component of any intervention (Gersten et al., 2005). To address fidelity, the number of bookmaking home visits was recorded and practitioners rated families' engagement in the bookmaking process. Intervention families received an average of 9.3 home visits (range 0 to 17; 3 families left the program) focused on book making strategies over a 7-month period. Staff ratings of family engagement during these visits averaged 4.01 on a 5-point Likert-type scale where a 5 indicated "enthusiastic, actively engaged during and between home visits."

Results

To address the first research question (early intervention providers and families would experience the family bookmaking activities as meaningful, enjoyable, and effective in promoting language development) descriptive data were drawn from practitioner and parent reports.

Early intervention practitioners indicated that the bookmaking activities fit into their current work (4.4 on a 5-point scale) and that families were excited about making books with their children (4.8). Example comments included: "It works for kids – especially those with speech delays. They participate more, talk more, gets them to point at things and speak, it gets the family involved." "A huge benefit is leaving something concrete and familiar with the family. Then parents can see how it's related to their goals for their children and they have something to work on when they are on their own." "I have been able to get parents to work with their children more on their own." "The books lend themselves to almost any goal."

Parents also completed a questionnaire and were interviewed at the end of the study. Parents reported enjoying the bookmaking visits (4.5 on a 5-point scale) and that the books were helpful for their children's language development (4.1). Example comments included: "He was able to tell what he was doing and talk about it." "Because he was the main character of the book, he was in all of the pictures [and] making the things he liked. He recognizes more words."

The second research question, whether participating parents would increase their use of language-supporting behaviors, was addressed through comparative analyses of maternal language supporting behaviors from the videotaped and coded observations. At pretest, there were no significant differences between mothers in the family bookmaking group and those in the comparison groups on these variables. A series of hierarchical multiple regression models was then used to determine if participating in the family bookmaking approach uniquely

contributed to mothers' language-supporting behaviors above and beyond maternal vocabulary or education. Based on findings from initial group differences and correlational analyses, either maternal vocabulary and child age at pre-test or maternal education were entered as covariates in the first step of the regression analyses. Group status was entered on the second step. Thus, estimates of the influence of the intervention were tested after covariates were taken into account.

As shown in [Table 2](#), participation in the family bookmaking activities contributed to specific maternal language-supporting behaviors above and beyond covariates for maternal use of "wh" and open-ended questions. Participating in the family bookmaking group made a statistically significant contribution to maternal use of expansions, explaining an additional 9% of the variance, and to maternal use of open-ended questions, explaining an additional 6% of the variance, and to maternal use of "wh" questions explaining an additional 5% of the variance. Therefore, participation in the family bookmaking activities was a significant predictor for maternal use of expansions above and beyond maternal education and above and beyond maternal vocabulary and child age at pretest for "wh" and open-ended questions. No other statistically significant group differences were found for the other measured variables.

To address our third research question, whether language abilities would increase more among children in the family bookmaking group than among those in the comparison group, we examined their receptive and language skills at pretest and posttest. Two hierarchical multiple regression models were tested to determine if participation in the family bookmaking group contributed to children's posttest expressive language or receptive language scores above and beyond their pretest scores and maternal vocabulary. As shown in [Table 2](#), a model examining receptive language indicates that participation in the family bookmaking activities contributed to children's receptive language above and beyond maternal vocabulary and children's receptive language at pretest. Participation in the family bookmaking group made a significant contribution by increasing the variance explained in this model by an additional 5%. Therefore, participation in the family bookmaking activities was a significant predictor of children's receptive language above and beyond children's pretest scores and maternal vocabulary. No differences were found between groups on expressive language scores.

Discussion

These results suggest that the family bookmaking approach offers a promising strategy for engaging parents, increasing the quality of parent-child language interactions, and increasing children's understanding of language. The family bookmaking approach was well received by both parents and early intervention providers. All parents and providers reported that they saw these activities as beneficial for the children and easily usable in natural environments. The resulting improvements in children's receptive language skills and parents' use of language-promoting strategies are promising and consistent with other research demonstrating that parents can easily be taught to establish joint attention with a book, increase questioning with children, and respond to their children's questions; these behaviors lead to active communication and language use by children (Crowe, Norris, & Hoffman, 2004).

The sequence of activities that are part of the family bookmaking activities are evidently

effective in engaging parents in home visiting early interventions. These specific activities provided both a context and resources for language and literacy support. The context provided opportunities in which parent-child language interactions were more likely. The books that were made as part of the activities provided high interest literacy resources that elicited continuing language interactions between home visits. Practitioners were able to implement the family bookmaking activities as part of their day-to-day responsibilities after a short period of training.

The willingness of practitioners to implement the family bookmaking activities is evidence of the usability and feasibility of these activities for early intervention programs. Practitioners' values, current workload, and perception of family involvement responsibilities all contribute to their willingness to implement principles and practices of family-centered intervention (Campbell & Halbert, 2002). Family engagement and interest may reinforce practitioners when they do family-centered intervention. This may have been facilitated not only by the short period of training but also by the family bookmaking activities themselves. For example, in our study, one practitioner was hesitant to try the family bookmaking approach with a mother with clinical depression who kept the blinds closed and never left the couch during the home visits. After seeing the mother actively engaged during the family bookmaking activities, this practitioner reflected on several effective strategies that she could continue to use to engage this mother on future home visits.

The family bookmaking activities were developed to address the importance of engaging the family in early intervention. Early intervention has a strong influence on children's development when it is able to increase mothers' responsiveness and interaction with their children (Mahoney & Wiggers, 2007). However, much of early intervention practice consists of practitioners working directly with children on activities to facilitate their development (McBride & Peterson, 1997). Even in programs with minimal facilitation of parent-child interaction, parents are more involved in the program when coaching strategies are used to support parent-child interaction (Peterson et al., 2007). The family bookmaking approach was combined with a model in which parenting strengths are supported and parent-child interaction is facilitated, making these strategies inseparable. The Say-Ask-Expand (SAE) language-supporting strategies mothers were encouraged to use, as part of the family bookmaking activities, have broad research support and may have increased language interactions both during the activities and during other family activities between visits. The changes in the parent language-supporting behaviors that were present in a semi-structured context of mother and child reading a book together suggest carryover beyond the actual family bookmaking activities.

Our training for the practitioners emphasized engaging parents and facilitating parent-child interaction consistent with a developmental parenting model (Roggman et al., 2008). By incorporating language-supportive activities within that model, the family bookmaking activities resulted in gains in specific parent language-supporting behaviors and child receptive vocabulary. Even after just a few bookmaking visits, child language gains were evident. The power of this intervention strategy suggests broad potential. Although we expected more expressive language gains, the receptive language gains suggest that children's understanding of language is increased by the family bookmaking activities. The young age of the children and their developmental delays may result in slower gains in expressive language as these children often have fewer words than typically developing children.

Unfortunately, the intervention using family bookmaking activities was not delivered equally to all families. These variations were due to staff illness, family cancellations of home visits, and time taken by other program activities. Nevertheless, among those families who received the family bookmaking visits, mothers' increased their use of language-supporting behaviors, and children increased their receptive language more than the comparison group. Although the sample size was small and the participants were not randomly assigned, the results of this exploratory study show that these family bookmaking activities have promise for guiding early interventionist practitioners with a sequence of specific activities that match best practices and result in parent and child gains after only a few home visits. A more rigorous study with a larger sample and with improved implementation is needed to provide additional support for the effectiveness of this approach with diverse families.

Conclusion

In summary, the family bookmaking activities appear to offer an effective, concrete way for early intervention practitioners to work through parents to support children's language development by engaging parent and child in specific language-promoting conversations and incorporating these conversations into small photo-illustrated books for the family to keep. Mahoney and Wiggers (2007) have recommended that early intervention practitioners shift their practices from working directly with children to providing coaching and supports for parents to facilitate their own children's development through ongoing interesting activities and daily routines. The family bookmaking activities are consistent with this recommendation.

Lisa K. Boyce, Ph.D., Family, Child, and Human Development, Utah State University USA

Mark S. Innocenti, Ph.D., Early Intervention Research Institute, Utah State University USA

Lori A. Roggman, Ph.D., Family, Child, and Human Development, Utah State University USA

Cora L. Price, B.A., Early Intervention Research Institute, Utah State University USA

Vonda K. Jump, Ph.D., Early Intervention Research Institute, Utah State University USA

Gina A. Cook, M.S., Early Intervention Research Institute, Utah State University USA

Eduardo Ortiz, Ph.D., Early Intervention Research Institute, Utah State University USA

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Table 1

Characteristics of the Families Assigned to Intervention and Comparison Groups

Characteristic	Intervention (n = 21)		Comparison (n = 21)		t value	p value
	M	SD	M	SD		
Mothers' years of education	12.76	2.61	14.33	1.74	2.30	.03
Mothers' vocabulary raw score	40.00	5.45	44.29	5.00	2.62	.01
Household income	\$31,000	\$24,577	\$40,500	\$21,515	1.27	.21
Child gender (% female)	52		29		-1.58	.12
Child age in months	24.47	3.74	26.02	2.91	1.54	.14
Child expressive raw score (REEL)	45.10	6.97	37.67	10.05	-2.04	.05
Child receptive raw score (REEL)	45.48	8.24	47.29	12.57	-.83	.42

Table 2

Regressions Predicting Maternal Language Supporting Behaviors and Children's Receptive Language

Step predictors	t entry	t final	B	SEB	β	R ² step	ΔR ²	F change	df
Model A: Maternal use of expansions									
Step 1. Maternal education	1.5	2.01 ⁺	.84	.42	.33	.06			
Step 2.		1.84 ⁺	2.78	1.51	.30	.15 ⁺	.09	3.38 ⁺	34

Intervention or comparison group									
Model B: Maternal use of open-ended questions									
Step 1. Maternal vocabulary	2.68*	3.28**	.04	.01	.56	.17*			
Child age	.69	1.11	.07	.06	.18				
Step 2. Intervention or comparison group		1.84 ⁺	.71	.39	.31	.25	.08	3.39 ⁺	34
Model C: Maternal use of “wh” questions									
Step 1. Maternal vocabulary	1.21	1.82 ⁺	.13	.07	.32	.14 ⁺			
Child age	2.22*	2.61*	1.00	.38	.43				
Step 2. Intervention or comparison group		1.72 ⁺	3.979	2.31	.29	.21	.07	2.94 ⁺	34
Model D: Children’s receptive language									
Step 1. Receptive language pretest	5.48**	5.38**	.84	.16	.74	.55**			
	-.27	.48	.05	.11	.07				

Mat									
ernal									
vocabular									
y									
	-.37	.10	.06	.61	.01				
Chil									
d age									
Step 2.		1.77 ⁺	5.60	3.16	.22	.59**	.04	3.15 ⁺	33
Interventi									
on or									
compariso									
n group									

⁺ $p < .10$

* $p < .05$

** $p < .01$

REVIEWS

Music Review

Title: *Wild Things: Sounds of the Disabled Underground Vol 1*

Artist: Compilation

Producer: Heavy Load (Mastered by Al Scott at Metway Studios, Brighton)

Label: Get in or Get Out Records

Website: <http://www.stayuplate.org/>; <http://heavyload.org/>;
<http://www.myspace.com/disabledunderground>

Price: £5.00 Available for purchase at: <http://heavyload.org/news.html#tshirt>

Reviewer: Kevin Dierks

Do you like to stay up late and party with your friends, or do you prefer to tuck in early and listen to a new CD and read the latest *Review of Disability Studies* journal? If you find yourself stopping and contemplating these two options this probably means you have a choice. Thousands of people do not have the opportunity to make this choice. One group of musicians has made this disparity their personal mission, and this mission has resulted in a compilation CD called *Wild Things: Sounds of the Disabled Underground Vol 1*.

This mission was bred in a United Kingdom (UK) culture of punk music, bar scenes, and learning disabilities fostered by the creative genius of a band called Heavy Load. This rag tag, beer drinking, band of hard rockers became frustrated watching their fans get up and walk out on them at 8:45 p.m., not because they did not like the show, but because they had to return home for their staff's shift change at 10:00 p. m. Heavy Load are apparently not the kind of guys to take things lying down, and as a response created a movement called the "Stay Up Late Campaign." Their message is direct and in your face, as any good punk rock song should be: "We want to stay up late - we want to have some fun." More information about this campaign can be found at <http://www.stayuplate.org>.

During an ensuing tour, Heavy Load met many more artists with learning disabilities and once again headed off on a campaign launching *Wild Things: Sounds of the Disabled Underground Vol 1*. *Wild Things*, the inspired brainchild of Heavy Load, is a compilation album featuring 16 songs by 16 different artists. It is the first of what is expected to be more volumes featuring artists with learning disabilities from the UK. The music on this CD is just as amazing and unique as the background story. In addition, all the proceeds from the sale of this album go to support the "Stay Up Late Campaign."

The style of music on this album is so diverse, everyone is bound to find something they like. Styles include techno, pop, rock, blues, reggae, and of course punk. Rhythmic dance beats sit next to screaming punk rock riffs. Some tunes sound slightly familiar, and others are probably unlike anything you have ever heard. All are 100% original and unique as the artists themselves. The music is so different that if not for the "Stay Up Late Campaign" it would most likely never be found on the same CD. The common thread is all the artists having learning disabilities. If you want to be inspired you are likely to find something here. If you want to be reminded of the range of creativity of the human spirit this album is for you.

Some of the song lyrics directly reflect the experience of living with a learning disability, such as “That’s a Beautiful Thing” by Vanessa Ryan and Kick Me Ugly: “*It might seem strange to you, but nobody needs to be tuned, and that’s a beautiful thing in this world*” or “Stand Up” by Beat Express: “*Stand up, stand up for yourself, speak up, speak up for yourself.*”

Other songs are remarkably simple in their approach yet have the ability to take a listener to deeper places, such as Heavy Load’s song “Farty Animals” with only one lyric repeatedly repeated: “*Ooooooo farty animals,*” or Dean Rawat’s rendition of the English alphabet in a way you’ve never experienced if you have not heard his song “Alphabet.”

I encourage everyone to buy this album to support a whole new range of talented artists and support a movement for freedom. Isn’t that what rock and roll was supposed to be all about anyway?

Kevin Dierks has worked for over 20 years with large and small non-profit organizations in Hawai‘i and State government, from the front lines of program delivery to program management and systems change to support people with developmental disabilities and the communities and systems that surround us. He has a M.A. in Community Psychology and is a graduate of the select leadership development and training program, The National Leadership Consortium on Developmental Disabilities, as well as a graduate of the Disability and Diversity Studies Certificate program at the University of Hawaii. He is also Certified Professional Coach, and a professional musician.

Book Review

Title: *Negotiating the Special Education Maze: A Guide for Parents & Teachers, 4th Ed.*

Authors: Winifred Anderson, Stephen R. Chitwood, Deidre Hayden and Cherie Takemoto

Publisher: Bethesda, MD: Woodbine House, 2008

ISBN: 978-1-890627-46-1, Paper, 275 pages

Price: \$21.95

Reviewer: Michael Bailey

”When I use a word,” Humpty Dumpty said in rather a scornful tone, “it means just what I choose it to mean – neither more nor less.”

Lewis Carroll

We expect no simple answers to complex questions. At the same time we long for simple answers to simple questions. And they are in short supply.

In 1962 the United States Supreme Court in *Baker v. Carr* provided a simple answer to the question “who may vote?” The court opined “one man—one vote.” Simple enough, but we all have a way of making incomprehensible that which should be simple. Nearly 50 years on, one Presidential election is forever tainted and litigation over who may vote is at an all time high.

Congress has even gone so far as to enact the Help America Vote Act which in a few thousand words attempts to explain the simple one man—one vote rule.

Another seemingly simple question was addressed by Congress in 1975 with the passage of P. L. 94 – 142. To the question “can children with disabilities be educated with their peers?” congress said yes. That law became the Individuals with Disabilities Education Act and now, proving that governments can have a sense of humor, it is called the Individuals With Disabilities Education Improvement Act.

That law is startling in its simplicity. Every child with a disability has the right to a free and appropriate public education in the least restrictive environment. Congress chose to make this a right. A right, such as the right to freedom of speech, is not negotiable. Kids with disabilities get to go to school just like everyone else. And when they get there they must be educated in the least restrictive way. Congress even added a statutory method for achieving this. An Individual Education Plan for each child. This is pretty simple. It is not hard to understand. But it has proven hard to implement.

Like the simple premise of *Baker vs. Carr* legions of bureaucrats, functionaries, lawyers, administrators and reactionaries have created a system of complex federal rules, state rules, local rules and honored but bogus local customs to turn the simple dream of IDEA in to what can only be described as a maze of nearly incomprehensible gibberish.

Maze (a confusing network of passages) is well chosen as the title of the 4th Edition of *Negotiating the Special Education Maze: A Guide for Parents & Teachers*. Authors Winifred Anderson, Stephen Chitwood, Deidre Hayden, and Cherie Takemoto are a good mix of professional special education persons, scholars, advocates, and parents. And the great strength of the book is their ability to take into account the points of view of a number of players.

This expertise is helpful in creating a text that, in spite of the complexities of modern advocacy, is clear, concise and does what a reader would expect. It explains in understandable language the principles of IDEA, guides one through the IEP process, and concludes with transition to adulthood.

But what makes this work stand out and what justifies yet another edition is the focus on relationship building between families and professionals. Litigation, mediation, etc., are all well and good but are generally beyond the emotional and financial tolerance of families. This book is a fine guide to decision-making and a reminder of the importance of keeping the educational needs of children as the focus of attention.

The system is not a simple system to deal with and this book is not a simple thing to read. But it comes as close as we are likely to get to taking participants by the hand and guiding them through this maze of special education complexity. If their advice is followed – and that’s not a foregone fact – their work will help assure that when a child with a disability finally reaches his or her 21st birthday and is finished with school, there is a great probability that education will have prepared that child to lead a happy and independent life. And for that this book and its authors deserve our thanks.

The book is not particularly accessible to people with disabilities but it is certainly worth the purchase price and I recommend it to anyone.

Michael Bailey is the author of *Special education: A parent's guide to a child's success*. He is President of Disability Rights Oregon as well as Vice President of the National Disability Rights Network. He can be emailed at mtbclarion@comcast.net

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The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i 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 Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, 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.

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