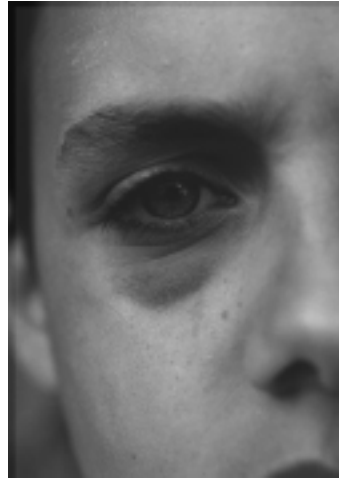


Breaking the Silence

By Marianne Valls

Do you think that your disability makes you immune to violence? As a woman with a disability, you would be wrong. In fact, there could come a time in your life when you could be dead wrong.

The Unheard Voice: Services to Abused Women with Disabilities,” a conference held on September 29, 2004, was designed to increase awareness among professionals and other interested parties about the high incidence of violence against women with disabilities. The con-



“Violence against woman with disabilities is an international problem.”

ference gave its participants some real insights into the scope of the problem and ways to search for resources in the community for victims of abuse.

The conference was a collaborative effort of the following organizations: NJ Coalition of Woman and Disabilities, Inc.; NJ Coalition of Battered Women; NJ Division of Disability Services, DHS; People Support Network of New Jersey; NJ Division of Deaf and Hard of Hearing, DHS; NJ Coalition Against Sexual Assault; Southern New Jersey Perinatal Cooperative; and the NJ Council on Developmental Disabilities.

In her keynote address, Heather B. Taylor, PhD, described the magnitude of the crisis. She is the Assistant Director of Research, Center for Research on Women

(continued on page 2)

for Women with Disabilities

I N S I D E

Hearing the Unheard Voice ③
 HIPPA Confusion ④
 Legislative Update ⑤

Breaking the Silence

(continued from page 1)

with Disabilities (CROWD) at the Baylor College of Medicine, Houston, Texas. Taylor pointed out that “violence against woman with disabilities is an international problem.” The occurrence of violence was found “to be 10 times more likely” among women with disabilities, and the woman with a disability endures the abuse for a longer period of time.

Taylor listed the various, and often unique, types of abuse that women with disabilities may experience. Studies show that four out of five women who have physical and/or cognitive disabilities will be sexually abused in their lifetime. Unfortunately, an abuser of a woman with disabilities often has a greater opportunity to punish her in unique ways simply because the woman is disabled.

Emotional abuse is also more prevalent among women with disabilities. Taylor related this story of a woman who endured this type of abuse for over twenty years. According to the woman who experienced this form of derogation, “At the onset of my disability my father stopped holding me, talking to me, touching me—this was a

daily experience. Prior to my disability we were close.”

The CROWD study compared 475 women with disabilities and 406 women without disabilities. Women with disabilities often encounter violence in situations that

Studies show that four out of five women who have physical and/or cognitive disabilities will be sexually abused in their lifetime.

are unique to their particular set of circumstances. These may include medical settings and relationships, and dealings with personal assistants. At times, victims may have “difficulty naming the violence.”

A number of proposals were suggested to deal with the crisis in Taylor’s keynote address and other workshops (which will be discussed elsewhere in this newsletter and in subsequent issues.)

“There is a need to create methods to identify women with disabilities in abusive situations.” Many shelters for battered women must be encouraged to become accessible

to the woman with disabilities, keep records of those women, and invite independent living centers to offer training.

Centers for independent living can play a big role in helping identify women in crisis. First, workers can be trained to recognize the signs and different types of abuse. They can learn to refer women to the appropriate agency. Centers can also advise women’s shelters on accessibility, disability awareness and sensitivity.

Despite the fact that Mark Malone is a man, he felt that as the coordinator for the Somerset County Office of the Disabled, it was important that he attend the conference. Malone thought it might give him some insight and increase his awareness concerning the subject. For example, he will now be alert should a consumer tell him that there is no alternative but to move from the person’s present situation. Malone felt it was one of the best conferences he ever attended.

With the approaching 15th anniversary of the passage of the Americans with Disabilities Act (ADA), it seems that the voice of the disability community remains unheard in many areas. However, none appears more urgent than the plight of the abused woman with a disability. ■

Hearing the “Unheard Voice”

A Guide for Services Providers

How to discover “the unheard voices” of women who are abused is a difficult problem. Health care workers and other providers who attended the conference workshop entitled “Stop the Violence, Break the Silence: Disability Service and Healthcare Workers Institute” learned the definition of abuse, the types of abuse common to women with disabilities, and how to deal with individuals who reveal abuse.

The presenters, Michelle “Shell” Schwartz, MA and Heather Anne Kamper, LMSW, are from an organization called A Safe Place (a safety awareness program) based in Austin, Texas. Beside statistics, their workshop supplied definitions of caregiver and caregiver abuse. Their workshop also provided useful materials, which dealt with various aspects of domestic, and/or caregiver abuse.

According to A Safe Place the definition of caregiver is: “One or more persons assisting another person with the tasks which the individual would typically do (for himself) if he did not have a disability” (Litvak, 1991). Materials handed out at the presentation identify family

members, friends, or hired employees as potential caregivers.

Abuse is defined as “the use of power in a relationship where the individual with a disability should have the right to absolute safety in his or her environment.” Caregiver abuse refers to the exertion of a caregiver’s will over the person with a disability. Abuse by a caregiver often involves more than physical injury. “Overuse of restraints, medication, or keeping an individual awake” are also considered forms of physical abuse.

Abuse may also include a long list of psychological mistreatment. Denying an individual their right to decision-making is a type of emotional exploitation. Making derogatory remarks about one’s disability is verbally abusive and should not be tolerated. Denying access to the individual’s financial resources is also caregiver abuse.

A crisis center for victims of domestic violence means little to a woman with a disability if there are physical barriers that prevent her entrance to the facility. Therefore, it is imperative that shelters and agencies dealing with all forms of abuse comply with the Americans with Disabilities Act (ADA). It is important to note that “Com-

munity Development Block Grants (CDBG) and Home Investment Partnership Programs (HIPP) may have funds available for accessibility modifications for existing shelters or new construction.” For further information, service providers should consult their local municipality or area HUD office.

Program access is just as critical as physical access. Perhaps the service provider’s reaction to a victim’s report of abuse is just as crucial. Like every other woman, a story of abuse told by a woman with a disability must be believed. Individuals with disabilities are all too frequently dismissed as not knowing what they are talking about. It is important to “validate” the feelings of a person who has suffered harm at the hands of another. Having correct information is imperative for reporting the abuse to the authorities.

Although the emphasis of this article is the role of the service provider, people with disabilities must be ready to reveal abuse. Today, more providers are willing to listen to victims who cry out for help. But you must be your own best friend, and cry out loudly for help!

—Marianne Valls

HIPPA Confusion

By Paulette M. Eberle

The Health Insurance Portability and Accountability Act (HIPPA) was passed in 1996 to protect confidential healthcare information by improving security standards and legislation on privacy. In an attempt to keep up with technology, the United States Department of Health and Human Services has issued new regulations under HIPPA.

HIPPA provides specific standards for protecting patient information during electronic transmission. It also offers guidelines for medical professionals and their office staff for dealing with this information.

While the new HIPPA Privacy Rule became effective on April 14, 2003, the HIPPA Security Rule will not become effective until April 21, 2005. The hundreds of pages of new regulations have healthcare professionals thoroughly confused. Patients across the country have found themselves in nightmarish situations because of this confusion.

There have been reports of delayed treatment because doctors do not want to transmit necessary medical information to other healthcare professionals involved in the patient's care. Patients are being asked to sign blanket HIPPA release forms before treatment can begin and some



family members are being denied the right to participate in a loved one's care.

These regulations were intended to protect a consumer's private healthcare information from unscrupulous use, not to impede their medical care. Training of healthcare professionals will be essential to ensure compliance with the new regulations without endangering patients.

A private doctor or healthcare facility can cer-

tainly transmit pertinent information to other caregivers without a signed authorization. The minimum security standard does not apply in the case of disclosure of information for treatment.

Family members who are involved in the patient's care can also be given information without a signed consent form. If a patient is not present or is not competent, the doctor may use his/her discretion whether to disclose

information or not. The patient may also have a family member present in the examination room without signing anything to have this privilege. However, if a family member is requesting copies of the patient's personal healthcare documents, a signed release form will be

required before any documents are sent.

Can friends, acquaintances and family members still get general information about a patient from calling the hospital? Yes, there is nothing in the new regulations that forbids a hospital from disclosing a patient's room number, phone number in that room or the general condition of the patient. On the other hand, if a friend or family member

(continued on page 5)

happened to work at the hospital and used his/her position to gain access to the patient's private information, i.e. test results, diagnosis, billing information, the facility would be in violation of the law and the facility could be open to a lawsuit.

For persons with disabilities, communication with their healthcare professionals is crucial. What happens if a person needs to use another person to facilitate this communication, such as in the case of appointment reminders or referral information? One of the rights under the privacy act is the right to request the way information is communicated to you. This privacy rule also allows the healthcare provider to leave a message on an answering machine. However, the provider should use care about how much information is given when using an answering machine.

These are only a few of the issues that effect consumers under the new HIPPA regulations. Doctors, healthcare facilities, insurance companies and other healthcare professionals are struggling to understand and comply with the new rules. We will keep you informed about the issues most pertinent to you, as a consumer, as April 21, 2005 approaches. ■

LEGISLATIVE UPDATE

BY ANITA CLAVERING



Legislation was passed on June 14, 2004 establishing the New Jersey Prescription Drug program to reduce prescription drug prices for consumers with disabilities, senior citizens, working families, and other low-income individuals. A.1593/S.590 includes a discount card and the establishment of an advisory council comprised of the Commissioners of Health and Senior Services and Human Services, medical professionals, pharmacists, and health care consumers.

The federal Pharmaceutical Market Access and Drug Safety Act of 2004 (S.2328), co-sponsored by Senators Byron Dorgan (D-North Dakota) and Olympia Snowe (R-Maine), was introduced in April. The bi-partisan bill would legalize and regulate importation of prescription drugs.

Former Governor James McGreevey signed legislation creating the first nationwide facility for stem cell research on May 12, 2004 at a forum of 200 people at the University of Medicine and Dentistry (UMDNJ). The Stem Cell Institute of New Jersey will be

a joint effort between UMDNJ and Rutgers University, supported by the state and funded through a public/private partnership. The Institute's mission will be to advance and fund research to find cures for heart disease, cancer, diabetes, multiple sclerosis, Parkinson's disease, Alzheimer's disease, spinal cord injuries and other diseases.

Other legislation suggested by members of the Women's Health Care Task Force were reviewed and/or voted on again in 2004. One was the establishment of a public awareness campaign on post-polio sequelae, introduced as A.2486 and passed by the General Assembly that year.

The bill was re-introduced as A.1988 in February 2004. It requires the Commissioner of DHSS to develop educational materials with health care facilities and providers with expertise in post-polio sequelae to be made available to local boards of health, medical professionals, hospitals and clinics for distribution to consumers.

Another bill, A.336, providing in-network benefits to patients with disabilities for services provided by out-of-network providers under certain circumstances, passed the General Assembly in March 2004, and awaits action in the New Jersey Senate.

New Jersey Women with Disabilities Health Care Task Force:

Holly Wetscher, chair
Christine Cripps-Barker
Patty Bennett
Kate Blisard
Janet Chiorello-Ellis
Anita Clavering
Barbara Coppens
Adelaide Daskam
Nicole L. Davis
Paulette Eberle
Ilise Feitshans
Christine Fraser
Marilyn A. Gelman
Betty Gill
Pat Krupka, staff
Josephine Messina
Janice Ortiz
Dottie Owens
Sandra Pinkerton
Marianne Valls
Mary Kay Weber

New Committee for Men with Disabilities

In the inaugural issue of this newsletter, we described how a steering committee of women with disabilities, supported by the NJ Council on Developmental Disabilities, embarked on a journey to improve the quality of health care and assure that health professionals are knowledgeable and sensitive to their needs.

Now we're being joined in this *Health Access* effort by a committee of men with disabilities, under the leadership of Council member Stanley Soden. During the coming year, they will develop a survey for men with disabilities to determine health-related issues and barriers, and follow-up with a statewide conference in the fall of

2005.

Over time, we envision that these two groups will be merged into one, viable People with Disabilities Healthcare Task Force, with a single, small leadership committee made up of members from each group's steering committees.

In the process, we will unveil a new membership status to seed a growing network of persons interested in the issues of health care. Membership benefits will include receiving Health Access newsletters, notices about upcoming events & conferences, opportunities to join in advocacy activities and legislative efforts, public education speaking engagements and more!

for Women with Disabilities

SSEFCCA
H-I-L-A-R-E-H

Return Service Requested

FIRST-CLASS MAIL
U.S. POSTAGE
PAID
TRENTON, N.J.
PERMIT NO. 21

NJ Council on Developmental Disabilities
PO Box 700
Trenton, New Jersey 08625-0700