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health Alert

STRENGTHENING THE HEALTH CARE SYSTEM'S RESPONSE TO DOMESTIC VIOLENCE

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Responding to Abuse Against Women with Disabilities:

Broadening the Definition of Domestic Violence

By Mary Ann Curry, R.N., D.N.Sc. and Fran Navarro

It is critical that health care providers recognize and respond to an expanded definition of domestic violence when serving women with disabilities.* Women with disabilities tend to suffer from additional types of abuse, for longer durations, and at the hands of a greater number of perpetrators. The Center for Research on Women with Disabilities (CROWD) found that women with physical disabilities are more likely to use every major category of healthcare provider and facility (including public health clinics and emergency rooms) within a given year, and that ninety-one percent see one or more specialists during that time. Additionally, twenty-four percent of women with disabilities seek care from alternative health care providers such as cuanderos, homeopathists, and acupuncturists.(1) These facts place a unique responsibility on healthcare providers to identify and respond to the unique abuse women with disabilities face.

"My access to the world is the phone...she just took the phone and put it somewhere where I couldn't get it...I couldn't yell enough to attract anyone. It was a nightmare".

name of survivor withheld for safety reasons

Mary Ann Curry, R.N., Oregon Health & Science University School of Nursing

A Delphi survey conducted by Berkeley Policy Associates in 1995-96 found that women with disabilities rated caregiver abuse and domestic violence as the number one priority concerning research and policy issues.(2) While the same high rate of lifetime physical, sexual and/or emotional abuse was found among women with physical disabilities and nondisabled women, women with disabilities were more likely to experience abuse by health care providers and personal assistants, both formal and informal, family members, intimate partners, friends or professionals and for longer periods of time.(3) As health care providers begin to use an expanded definition of domestic violence in their

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practices, they must recognize that abuse by a caregiver is intimate partner violence and they must screen for abuse by paid and unpaid caregivers. It is important to recognize the complex relationship between women with disabilities and the people who provide their personal care. The fear of not having basic physical needs met when assistance is not provided *is* identified as a powerful method by which people with disabilities have been victimized. The power dynamics and resolution of subsequent abuse may become more difficult or confusing if the caregiver is also a family member or intimate partner. This increases the chance the abuse will remain hidden because of fears of losing the relationship or fear of being institutionalized. If the person who is abusing you is also your caregiver, who will provide your personal assistance if you leave?

According to The Survey of Income and Program Participation (SIPP), a multi-panel, longitudinal survey conducted in 1995 by the U.S. Census Bureau, an estimated 21.3% of the female population or 28.6 million women and girls with disabilities live in the United States.(6)

Forms of Abuse are Unique

Women with disabilities are certainly vulnerable to the types of physical, sexual, emotional, and financial abuse experienced by women without disabilities. However, it is essential to recognize that these types of abuse may be experienced in unique ways. For example, disability-related physical abuse may include being handled roughly during a transfer, being asked to stand for an intolerable length of time or being restrained. Disability-related sexual abuse may include demanding or expecting sexual activities in return for help or being left naked or exposed. Disability-related emotional abuse may include threats of abandonment, belittling, or accusation of faking. Examples of disability-related financial abuse include personal assistance providers who don't work the expected hours, steal money or personal items, or misuse debit or credit cards. Forms of caregiver/intimate partner abuse may also include: forms of threats of harm or abandonment, intimidation, emotional abuse, isolation, minimizing, justifying or blaming, withholding, misusing or delaying needed supports, economic abuse and caregiver privilege.

In addition, women with disabilities are at risk for experiencing abuse that is specifically related to their disability support needs, such as medication abuse, refusing to provide essential care, and disabling of equipment. Medication abuse includes being given too much, too little, or denied essential medication. Refusing to provide essential care can not only be uncomfortable, but life threatening. Some examples include refusing to turn a person with pressure sores, not providing adequate fluids or refusing to help with

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The Family Violence Prevention Fund (FVPF) is a national non-profit organization focusing on domestic violence prevention, education and public policy reform. Founded in 1980, the FUND has developed pioneering stategies to address the problem of domestic violence in the justice,health care,child welfare,workplace and communication fields.

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Power and Control in an Abusive Care-giving Relationship

Intimidation

Raising a hand or using other looks, actions, gestures to create fear; Mistreating service animals; Destroying property and abusing pets; Displaying weapons

Emotional Abuse

Punishing or ridiculing; Refusing to speak and ignoring requests; Enforcing a negative reinforcement program or any behavior program the person doesn't consent to; Ridiculing the person's culture

Isolation

Controlling access to friends, family and neighbors; Controlling access to phone, TV, news; Limiting employment possibilities because of caregiver schedule; Discouraging contact with the case manger or advocate

Minimize, Justify, and Blame: Denying or making light of abuse

Denying physical and emotional pain of people with disabilities; Justifying rules that limit autonomy, dignity, and relationships for program's operational efficiency; Excusing abuse as behavior management or caregiver stress; Blaming the disability for abuse; Saying the person is not a "good reporter" of abuse

Withhold, Misuse, or Delay Needed Supports

Using medication to sedate the person for convenience; Ignoring equipment safety requirements; Breaking or not fixing adaptive equipment; Refusing to use or destroying communication devices; Withdrawing care or equipment to immobilize the person; Using equipment to torture people

Economic Abuse

Using person's property and money for staff's benefit; Stealing; Using property and/or money as a reward or punishment; Making financial decisions based on agency or family needs; Limiting access to financial information and resources

Caregiver Privilege

Treating person as a child, servant; Providing care in a way to accentuate dependence/vulnerability; Making unilateral decisions; Defining narrow, limiting roles and responsibilities; Denying the right to privacy; Ignoring, discouraging or prohibiting the exercise of full capabilities

Coercion and Threats

Threatening to hurt the person, withhold basic support and rights, terminate the relationship and to leave the person unattended, report noncompliance with a program, using more intrusive equipment; Pressuring the person to engage in fraud and other crime; Using consequences and punishments to gain compliant behavior

This information is adapted from the Power and Control Wheel created by the Wisconsin Coalition Against Domestic Violence and the Wisconsin Council on Developmental Disabilities to address abusive care-giving relationships and is based on the power and control wheel developed in Duluth MN.

toileting. Disabling or withholding equipment is a very serious form of abuse and may include putting a walker out of reach, removing the battery from a power wheelchair, or taking a phone away. Taking someone's phone away is similar to locking the person in a closet.

Because these forms of abuse are little known, women with disabilities are further isolated and underserved by providers whose non-recognition creates a barrier to providing them with an option to disclose the abuse.

What Can Health Providers Do?

Women with disabilities need to be provided with opportunities to identify whether or not they are experiencing abuse. Advocates and health providers need to ask about specific behaviors, such as: "Has anyone you know damaged or kept you from using a phone, wheelchair, cane, walker, or other assistive device?" Or, "Has anyone refused or neglected to help with an important personal need such as using the bathroom, eating, or drinking?" Women who disclose they have experienced abuse need to be further assessed for factors that may place them at increased risk, such as not having a backup personal assistance provider or experiencing a serious health condition, such as diabetes, that if neglected could become dangerous. Safety planning, in these cases, can include arranging for backup caregivers and packing a bag with money, copies of keys, important documents, spare assistive equipment, extra prescriptions and medical supplies and a change of clothes. Additional examples of screening questions, risk factors and safety planning can be found in a brochure titled: Women with Disabilities: It's Your Right To Be Safe From Abuse, produced by the Oregon Institute on Disability and Development's Center on Self-Determination, available online at http:cdrcohsu.edu/selfdetermintion/violence.html and a safety card is available from CROWD (www.bcm.tmc.edu/crowd).

Traditionally, health care providers have not generally considered addressing the abuse that exists for their clients with disabilities as part of their role or responsibility and have not recognized the interconnectedness of the abuse and the disability. As health care providers assume the responsibility of screening for domestic vio-

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lence, they must do so in a culturally competent manner. This means screening the patient privately, not relying on a partner, friend, family member or other caregiver. As with all patients, spend some time alone with them, using a professional translator, including sign language translators, if necessary, to talk about and screen for abuse with the assurance that this a confidential conversation. When working with women with developmental disabilities, providers should allow them to "speak" for themselves and not rely on others to interpret their actions. A common misconception that individuals with developmental disabilities do not comprehend their experiences and therefore do not have emotions or thoughts to respond to abuse can lead to referrals not being made. The ability for health care providers to treat an abused person with disabilities is limited by perceptions, not skills.(4) In addition, a common myth exists, even within the health care setting, that women with disabilities are asexual and not only would it be unlikely for them to be in a relationship, but that others would pity them rather than abuse them. It is not unusual for women with disabilities to face doubt when they disclose abuse to their health care provider. It is essential to validate the woman's experience and address her abusive environment as such.(5)

> *"You finally say, 'Okay this is it. I'm going to do whatever I can to change this marriage.' And by the way, can you bring my scooter to me so I can leave you?"*
>
> name of survivor withheld for safety reasons

Unfortunately, because of isolation and repeated exposure to mistreatment, many women with disabilities may not recognize that they have been abused. As one woman reported, "I never knew it wasn't supposed to hurt when someone combed my hair". Health care providers must keep in mind that their interaction with women who are victims of abuse may be the only time a woman is asked about violence and the only opportunity a woman has to disclose the abuse. Women need to be told that it is not right to experience hurtful behaviors and perhaps even against the law. Once providers screen for and identify the abuse women with disabilities face, they should be prepared with policies and protocols regarding assessment, intervention, documentation and referrals. Health care providers should provide information on available resources and assist with appropriate safety planning. An excellent guide to caregiver abuse and disability-specific safety planning entitled Stop the Violence, Break the Silence has been developed by Safe Place in Austin, Texas. It is available at www.austin-safeplace.org.

Finally, it is important to recognize that women with disabilities generally have had extensive exposure to the health care system and a variety of health care providers. Unfortunately for many, these have been unwanted and often traumatic experiences. And for some, they have included abuse. Some of these abuse experiences are easily recognized as wrong, such as being touched inappropriately or being forced to have sex. However, women with disabilities identify other forms of abuse they considered just as hurtful and far more common. These include health providers who ignore or discount what they have to say; ignore, under medicate, or minimize physical pain; do not allow enough time to communicate; push beyond physical limits; and offer limited treatment options.

Breaking through the barriers that exist in addressing violence against women with disabilities is an important step for health care providers to make as well as an opportunity to view a disability as only one aspect of the person while treating the person as a whole. As providers take on the task of using an expanded definition of intimate partner violence, it is important to remember to screen for abuse not only by traditional perpetrators, but also by paid and unpaid caregivers, neighbors and friends. Providers should routinely screen for unique forms of abuse while alone with the patient and be prepared with the proper referrals. Because studies reveal that women with disabilities believe violence to be one of the most important issues in their lives and health care providers continue to be a consistent point of contact for women with disabilities, an opportunity exists for building bridges. In turn, health care providers can use this opportunity to open the line of communication with domestic violence advocates and the disability community (independent living centers, ARC and others) in order to work together in an effort to end violence against women with disabilities. As providers serve women with disabilities they should screen for domestic violence in a safe, supportive and

confidential environment, validate a woman's experience and provide referrals and resources, perhaps providing the first step toward overcoming barriers to ending abuse.

**There is little data available on violence against heterosexual men or lesbian, gay, bisexual, and transgender individuals with disabilities, however anecdotal evidence suggests that they are also vulnerable. Although this article focuses on violence against women with disabilities, consider screening all patients with disabilities for abuse and be sensitive to difficulties they may have with disclosure.*

Mary Ann Curry, R.N., D.N.Sc., Professor Emeritus of Oregon Health & Science University School of Nursing is currently engaged in research focusing on issues of family violence. With colleagues from nursing and other disciplines, she is studying women's risk factors for homicide from an intimate partner and the abuse that women with disabilities experience from care providers as well as intimate partners. Dr. Curry is also working on interdisciplinary projects aimed at helping women identify if they are in an abusive relationship, interventions for abused pregnant women, and educational programs regarding the abuse of women with disabilities.

Fran Navarro is a Senior Program Assistant at the Family Violence Prevention Fund and co-editor of the Health Alert publication. Ms. Navarro has created a resource packet containing studies, facts, tips sheets and tools specific to responding to domestic violence against women with disabilities. She also works closely with the California Clinic Collaborative, a diverse group of community health centers, on continuing medical professional education issues and facilitates support groups for children of divorce and separation.

Mary M. Oschwald and Laurie Powers, PhD from OHSU Center on Self-Determination assisted in the research and contributed to the writing of this article.

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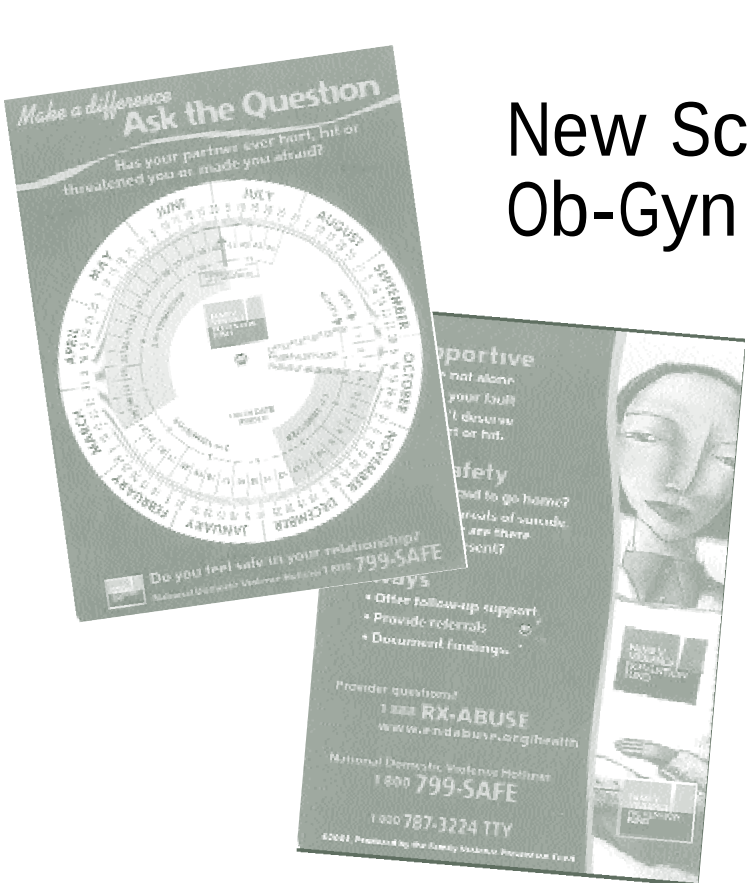

New Screening Tool for Ob-Gyn Department

The Family Violence Prevention Fund developed a new pregnancy wheel printed with domestic violence routine screening questions for use in OB-Gyn departments. Pregnancy wheels are used in most medical settings that serve women of reproductive age by clinicians, including medical assistants, health educators and pregnancy test counselors. The card reminds staff everytime they calculate anything related to birth control or pregnancy, to ask about domestic violence, posing simple questions like, "Are you being hurt, hit, or threatened?" "Do you feel safe in your relationship?" The back of the wheel provides information related to assessing safety, documentation, follow-up, and referrals.

The pregnancy wheels can be ordered online at www.endabuse.org/store or by calling 415-252-8089, TTY: 1-800-595-4TTY.

Screening for Violence in the Pediatric Setting

Mothers Support Domestic Violence Screening at Well-child Visits

A recent study by Gregory W. Parkinson, MD, Richard C. Adams, MD, and Frank G. Emerling, MD published in *Pediatrics* (Vol. 108 No. 3) found that almost 83% of mothers supported pediatricians asking about maternal domestic violence in the pediatric setting. While the American Academy of Pediatrics advises pediatricians to screen for domestic violence, only 17% of mothers had recalled being asked about it. Approval of domestic violence screening by pediatricians did not vary between women who did or did not have a history of violence. Additionally, the authors estimate that screening for violence took approximately five minutes and extra support staff was not required. These results indicate that time restrictions and maternal approval should not be seen as barriers and that routine maternal domestic violence screening can become part of a pediatric practice.

Adolescent Girls who Witness or Experience Violence at Increased Risk

A study by Abbey B. Berenson, MD, Constance M. Wiemann, PhD, and Sharon McCombs, MHSM published in the *Archives of Pediatrics & Adolescent Medicine* (Volume155) found that adolescent girls who witness or experience violence are at increased risk of multiple adverse health behaviors. Girls who witnessed violence were 2 to 3 times more likely to report using tobacco and marijuana, drinking alcohol or using drugs before sex, and having intercourse with a partner who had multiple partners. Girls who experienced violence, but did not witness it, were at increased risk of these same behaviors and were 2 to 4 times more likely than those who had neither witnessed nor experienced violence to report early initiation of additional health-risk behaviors such as intercourse with strangers, and drug use. Adolescent girls who both witnessed and experienced violence demonstrated 3 to 6 times greater risk of suicidal ideation or suicide attempts, self-injury, and use of drugs before intercourse than those who had not witnessed or experienced violence. Results of this study point to a need for screening for both domestic violence screening in the home and teen dating violence of adolescent girls.

Barriers to Screening

Mary J. Erickson, MD, Teresa D. Hill, PhD and Robert M. Siegel, MD conducted a study on what pediatricians perceive to be barriers for screening for domestic violence in the pediatric setting published in *Pediatrics* (Volume 108, No. 1). The study found that 64% were not aware of the American Academy of Pediatricians recommendation to screen routinely, 74% had never receive domestic violence training and 58% estimated the incidence of domestic violence to be less than 5% of their practice. Although 51% of the pediatricians screened families that they identified as high-risk only 8.5% routinely screened. The authors found that lack of education, office protocol, time and support staff were seen as the prime barriers to screening and conclude that greater efforts to educate pediatricians on domestic violence are needed for AAP recommendations to be accepted.

State Efforts to Address Domestic Violence in the Health Care Setting

Pennsylvania's Hospitals' Response to Domestic Violence

In an effort to better quantify Pennsylvania's hospitals' and health systems' commitment to domestic violence, the Hospital and Healthsystem Association of Pennsylvania surveyed their 250 member organizations. The survey looks at the organizational structures, screening, intervention efforts, staff training, public awareness initiatives and barriers to success. Of the hospitals that responded, the survey found that nearly 83% has a policy that specifically addresses domestic violence, one-third of respondents had a

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HCADV Organizing Contest Winner Announced

Thousands of health care providers, domestic violence advocates and others have participated in Health Cares About Domestic Violence Day since its inception three years ago. The Day aims to raise awareness that domestic violence is a health care issue, while providing clinical tools to support routine screening. An organizing contest was added to the 2001 "Screening to Prevent Abuse" packet in an effort to recognize and reward participants' innovative strategies. When Mimi Prada was informed that she had been selected as the 2001 Organizing Contest Winner she was overjoyed and exclaimed "I thought the competition would be too steep!" Prada, a Community Advocate from Alternatives for Women/Advocacy, Resources, and Education, Inc. (AW/ARE) has worked on the issue of domestic violence for the last three and a half years. Most recently, her work with three hospital systems and the Northwest District of the Pennsylvania Department of Health has helped bring the issue of domestic violence to the forefront of the public's mind.

Mimi Prada, recognized as a national leading organizer for the 2001 Health Cares About Domestic Violence Day. As part of her prize, she will receive $250 of clinical tools from the FVPF to further her advocacy within the health care setting.

With visible reminders like The Clothesline Project, a display consisting of more than 25 t-shirts decorated by adult, adolescent, and child victims of domestic and sexual violence, Prada introduced the strength and struggle of survivors to those who passed through hospital lobbies and waiting areas where the t-shirts were displayed. On-site advocates were available to offer resources and answer visitors' questions at The Empty Place at the Table—informational displays set up in lobby areas of several hospitals. In addition, domestic violence education and trainings were offered by the AW/ARE staff to health care providers within the facilities where the displays were located. Prada and the AW/ARE staff have been described by colleagues as "compassionate and dedicated" while continually "working to raise the bar of care for women in the community". AW/ARE's compassion may have been best recognized during their October 18th Candlelight Vigil and Speakout which joined community members to remember those who have both survived abuse and lost their lives to domestic violence.

As part of the third annual Health Cares About Domestic Violence Day, the Family Violence Prevention Fund is proud to recognize Mimi Prada's leadership and excellence in her pursuit to improve the health care system's response to victims of domestic violence. When asked what advice she would share with others seeking to improve the health care system's response to victims, Prada remarked "Don't give up! Keep laying the ground work!" She encouraged others to talk to enough people until one is found who has the passion and conviction to help the collaborative response move forward.

Health Cares About Domestic Violence Day is an annual event held the second Wednesday of October—this year's Day is October 9, 2002. Organizing packets will be available on-line (www.endabuse.org/health) and via hard copy beginning June, 2002. For more information, visit www.endabuse.org/health or call the National Health Resource Center on Domestic Violence (888) Rx-ABUSE, TTY (800) 595-4TTY.

State Efforts …

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domestic violence task force, and almost 23% had an onsite medical advocate. Three-quarters of respondents provide training and education on domestic violence awareness and intervention to all employees involved in direct patient care, one-third of respondents hold annual conferences on domestic violence, 27% conduct public awareness campaigns and 14% provide safety cards in women's restrooms. Although respondents mentioned several barriers to success, more than a third listed time/staff and financial constraints in response to an open-ended question. The complete findings entitled "Hospitals Respond to Family Violence: Every Person Has a Right to Live in a Home Free of Violence" describes the commitment that hospitals and health systems have made in preventing domestic violence and is available online at: http://www.haponline.org/about/top/

Call for Abstracts – March 4, 2002 Submission Deadline

National Conference on Health Care and Domestic Violence

September 26-28, Atlanta, Georgia

"Prevention and Response Strategies:
Pushing the Envelope"

Deadline for Abstract Submissions: March 4, 2002
Decisions Mailed: May 10, 2002

The Conference Steering Committee is now accepting presentation abstracts for review. The interdisciplinary continuing education conference, sponsored by major health and medical associations and government agencies, welcomes submissions from clinicians, researchers, administrators, advocates, and others who address domestic violence as a health care issue. Submissions can be made online at www.endabuse.org/health. For more information and complete guidelines, please visit our website or call 888-Rx-ABUSE, TTY: 800-595-4TTY.

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