We never expected to find violence. Who would have thought that women with disabilities would have a problem with the horrible experiences we see on TV and in the movies such as battering, rape, or the threats of such—unheard of, unimaginable. It was only one conversation with Dr. Sandra Cole at the University of Michigan, an advisor to the exploratory sexuality study that got our Center started, in response to a question about any topics of inquiry that we might have left out. “Abuse” was her quick suggestion and it put our antenna up. In the qualitative interview phase of that study we asked if the women had ever experienced anything that they would call abusive (Nosek, 1996). More than three-quarters of the women spoke to us at length about a wide variety of abusive experiences, from long ago in childhood to lifelong abuse, from all the worst we’ve seen on TV to forms of terror only a woman with a disability could understand.

The nation-wide survey that was developed from the themes that emerged from the interviews confirmed the magnitude of this problem. We found that out of 429 women with disabilities and 421 women without, 62% reported experiencing some kind of abuse at some time in their lives; 52% experienced physical and/or sexual abuse. There was also no significant difference between the groups in the percentage of women who were
Currently in abusive situations, about 13% (Nosek, Howland, Rintala, Young, & Chanpong, 2001; Young, Nosek, Howland, Chanpong, & Rintala, 1997; Nosek, Howland, & Young, 1997).

In the open-ended questions in the abuse section of the survey, some women added multiple typed or hand-written pages to describe their experiences. It was from these descriptions that we identified one of our most important findings—that women with disabilities experience the same range of horrors as women in general, but in addition they experience types of abuse that are specifically related to their disabilities (Nosek, Foley, Hughes, & Howland, 2001). We concluded that disability is not a protective factor against abuse; indeed, it often serves to reduce a woman’s emotional and physical defenses. Although the nature of the abuse revolves around the dynamics of power and control, the presence of disability or the context of a disability-related setting or relationship opens new channels for the expression of those dynamics.

Aspects of abuse that were specifically related to disability fell into two broad categories: 1) variations on common forms of emotional, physical, and sexual abuse that would not be as likely if the women did not have a disability, and 2) abuse that occurred in a disability-related health care or service setting or re-

Although the nature of the abuse revolves around the dynamics of power and control, the presence of disability or the context of a disability-related setting or relationship opens new channels for the expression of those dynamics.
relationships. Medical settings are particularly restricting and often remove from girls and women what defense mechanisms they may have, such as putting their wheelchairs or other mobility devices out of reach, and separating them from the parent or attendant who brought them. One woman reported, "At the clinic, my neurologist once made me take all my clothes off and began fondling me." Another wrote, "The orthotist told me he had to put his finger in my vagina to be sure the (artificial) leg fit right."

For assistance received both from family and non-family paid workers, participants described abuses of the helping relationship, including threats of withholding assistance, physically rough treatment, inappropriate touch during hygiene care, refusal to honor the woman's choices and preferences, and stealing money and property. Often these abuses are perpetrated when the women is in a particularly vulnerable situation where she cannot defend herself, such as in bed or on the toilet, when she is ill or experiencing an exacerbation of disability symptoms, or in public and needing assistance. Some examples of reports include, "[My] caregiver had an affair with my husband when I got sick." "She (my attendant) smeared food in my hair and face three times; she would hold me down in the bed and say horrible things to me. I would cry a lot." The need for personal assistance
and the cost and difficulty of locating and retaining persons outside the family to provide that assistance can make women with disabilities more tolerant of abusive behaviors.

Additionally, the abuse experienced by women with disabilities may not be perceived as abuse. For example, a woman with post polio who had been left on the toilet for hours and had her diabetes medication moved out of her reach may indeed suffer intentional physical injury as a result, but she would not be likely to label it as physical abuse. A woman with spinal cord injury whose attendant fondled her while helping her get dressed may not consider that as being forced into sexual activity and would probably not label it as sexual abuse. The forms of intentional and unintentional neglect that many women with disabilities experience, such as having no one able or willing to turn them at night or help them with personal hygiene, can be physically very injurious. These actions, however, are generally not considered by most researchers as falling within the realm of abuse and are not included in abuse screening efforts. These findings indicated a need for the development of disability-sensitive abuse screening instruments, and development and testing of interventions to assist women with disabilities in recognizing abuse, protecting themselves in abusive situations, and removing themselves from potentially
abusive relationships and situations. They also raised the question of how abuse may affect disabled women’s physical and mental health, provoking secondary conditions such as broken bones, skin ulcers, infections, sexually transmitted diseases, and depression.

The following report summarizes the results of our efforts to follow up on these findings. With funding from the Centers for Disease Control and Prevention, we were able to design and implement three different studies under the same project. We have organized our report in seven chapters as follows.

Chapter I, *Dynamics of Violence Against Women with Disabilities: A Qualitative Study*, comprised the first phase of this project. This was a study to understand more about the dynamics of abuse in the context of disability, using in-depth interviews of 14 women who had experienced and resolved violent relationships. Some had the onset of disability prior to experiencing violence, others acquired disability as a result of experiencing violence and further impairment from the continuation of that violence. Our main interest was in how they were able to resolve the abuse or leave the violent relationship. The women identified several potential interventions that could decrease the risk of abuse if implemented. These interviews yielded information about childhood experi-

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ences that appeared to increase the woman’s vulnerability for abuse. They also identified multidimensional factors in adulthood that contributed to the continuation of abusive relationships, such as the abuse of alcohol and other drugs, lack of education, untreated depression, and the presence of other mental illness. The primary barriers for getting help for the abuse included the fear of retribution, the woman’s health, and lack of mobility and/or transportation. Spirituality and/or a faith in God provided the strongest theme in the women’s recovery.

Chapter 2, Development of the Abuse Assessment Screen-Disability (AAS-D), reports on the development of an abuse screening tool that would be practical for use in service or clinical settings. Starting with the Abuse Assessment Screen (AAS), a two-item instrument developed and tested by Soeken, McFarlane, Parker, and Campbell (1998), we worked with Dr. Judith McFarlane at Texas Woman’s University to construct two additional items that would address the withholding of orthotic devices or medication and the withholding of needed assistance. Heroic effort on the part of investigators and staff resulted in the recruitment of 511 women from local public and private specialty clinics. The participants completed a face-to-face, orally administered questionnaire. We did not collect identifying information in order to of-
fer the women protection against possible retaliation by their perpetrators if their identities were ever to be revealed. By making this an anonymous study we sacrificed our ability to contact the participants again for follow-up or for future studies. Fifty of the women (about 10%) screened positive for abuse. By adding the two disability-related items, we were able to identify 20% more abused women than if we had used only the two general items of the AAS (McFarlane et al., 2001).

The majority of women in this phase of the project had a minority or low-income background and about the same education level as the general population. This was a distinct change from the mostly white, middle to upper income, highly educated, well-insured individuals who respond to mailed questionnaires and who too often comprise the samples used in disability-related investigations. These data, therefore, provided a rich resource for multiple analyses including those that are reported in the four chapters described below.

Chapter III, Demographic, Disability, and Psychosocial Characteristics of Abused Women with Physical Disabilities, reports on our investigation of the association of abuse with other psychological and physical health factors, and disability-related and demographic information. By the time our screening

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interviews had detected more than 10 women who had experienced abuse in the past year and our field staff had recorded information about the related trauma, we decided that we would obtain a more complete portrayal of the women’s experiences by adding measures of depression and stress to our protocol. This was a decision supported in the literature by the highly documented association between abuse and psychological distress. Thus, while the full sample had 511 participants, this analysis was based on data from a subsample of 415 women who had completed the measures of stress and depression. The findings from this analysis suggest that women with disabilities who are younger, more educated, less mobile, more socially isolated, and who have higher levels of depression may have a higher likelihood of experiencing abuse.

Chapter IV, *Perceived Stress and Women with Disabilities*, summarizes our examination of the extent that current abuse and other salient factors contribute to stress among women with disabilities beyond demographic and disability-related factors. This analysis was based on the subsample of 415 as described above. Our results indicate that women with physical disabilities may be at risk for greater stress if they are lacking social support, are experiencing high levels of pain, and/or have current abusive experi-

*The findings from this analysis suggest that women with disabilities who are younger, more educated, less mobile, more socially isolated, and who have higher levels of depression may have a higher likelihood of experiencing abuse.*
ences. Moreover, perceived stress appears to be greater for women who are younger, and who have less income, lower levels of mobility, and greater need for personal assistance services.

Chapter V, *Depression and Women with Spinal Cord Injury*, reports on an exploration of the phenomenon of depression in this population. Of the 511 participants in the full sample, 81 women had an SCI, 64 of whom completed the depression instrument. These 64 women comprised the sample for this study. In this study, 59% of the women with SCI reported a level of depression indicating risk for clinical depression, and depression scores were significantly higher for the women reporting current abuse compared to women not reporting abuse.

Chapter VI, *Safety Planning Intervention*, summarizes the third phase of the grant. This part of our project involved a pilot study of the development, implementation, and evaluation of a safety planning group intervention designed to educate and raise both awareness about abuse, and self-efficacy for implementing a safety plan among women with physical disabilities. We identified the need for this study from our previous research findings suggesting that women with disabilities do not often have the opportunity to learn about safety planning in ways that are responsive to their physical limitations and living situations.
situations. Given this need, we determined that it was imperative to develop a program to include awareness raising and educational activities designed to enable women with disabilities to learn skills and strategies for reducing their vulnerability and increasing their power to protect themselves. The program that we designed was pilot-tested successfully with 50 women with physical disabilities, and it resulted in significant and positive pre- to post-test changes on measures of knowledge and self-efficacy related to violence. The feedback from the women participating was highly positive. A videotape of the safety intervention program is in production, and we will apply for funding to make it available to service providers and test the efficacy of the program with a larger sample.

Chapter 7, *Disseminating the Findings*, includes a report on our intensive dissemination of the results of these studies to women with disabilities, programs for battered women, disability service providers, medical practitioners, and researchers. An average of four presentations and three publications per year have been delivered at abuse or disability-related professional meetings. Several manuscripts are in the preparation stages or have been published, and additional manuscripts will be prepared and submitted in the future. Two fact sheets summarizing our findings on violence and abuse were presented for us by Liz.
Savage of the Arc to the U. S. Congressional Caucus for Women's Issues Briefing on Domestic Violence at the request of Representative Schakowsky (see Appendix A). The briefing was attended by members of Congress plus advocates and service providers from the women's/domestic violence community. It was filmed by Lifetime TV for an educational video they are doing on domestic violence.

All publications prepared for both professional and consumer audiences will be posted on the Internet using our World Wide Web page (http://www.bcm.tmc.edu/crowd/).

We are pleased to report to the CDC that we have successfully achieved each of the objectives set forth in the grant. We extend our appreciation to JoAnn Thierry, our project officer, and the other officials from the Office on Disability and Health for their encouragement and guidance throughout this project. We are especially grateful to our valued advisors, Doctors Judy McFarlane, Patricia Mullen, and Jan Groff. We also acknowledge the contributions of the 511 patients and the medical staff of the Harris County Hospital District, Baylor-Methodist International Multiple Sclerosis Clinic, and the Institute for Rehabilitation and Research for the privilege of working with them. We hope that this report and the many publications to follow will serve to set the stage for Two fact sheets summarizing our findings on violence and abuse were presented for us by Liz Savage of the Arc to the U. S. Congressional Caucus for Women's Issues Briefing on Domestic Violence.
the next epoch of research on violence against women with physical disabilities. We are grateful to have had the opportunity do this very important research on behalf of women with disabilities. We do feel, however, that we have only begun to chip away at the cold and treacherous iceberg that results in the victimization, trauma, and other distress of abused women with disabilities.

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