

**A CALL TO ACTION:
ENDING CRIMES OF VIOLENCE AGAINST
CHILDREN AND ADULTS WITH DISABILITIES**

**A Report to the Nation
2003**

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PREFACE

This is a Report to the Nation on ending crimes of violence against children and adults with disabilities. This document is a collation and analysis of information from the National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities that was conducted on May 6 – 7, 2002 and from an independent review of the clinical and research literature. This Conference represented the first attempt to address, at the national level, both domains of prevention and intervention in violence against children and adults with disabilities of all types. In the past, national conferences and workshops were more specific in their focus. For example, in 1995, on behalf of the National Center on Injury Prevention and Control, Centers for Disease Control and Prevention, Dr. Michael Marge coordinated a track on “Violence as a Cause of Disability” as part of the National Conference on Violence Prevention. The purpose of the track was to identify effective ways to prevent persons with disabilities from becoming victims of violence and highlighted the importance of this topic and the need for more research and valid data about the magnitude and scope of the problem. In October 1999, the Department of Justice sponsored a workshop chaired by Dr. Joan Petersilia on effective ways to intervene after an individual with a disability is victimized by crime. Although there was some discussion about preventing other persons with disabilities from becoming victims, the major focus and the resulting report refer to interventional approaches for crime victims with developmental disabilities. The workshop was one of the activities supported under the provisions of the Crime Victims with Disabilities Awareness Act (Public Law 105-301).

The National Conference reported here was sponsored by twelve organizations and agencies (see Appendix A). The sponsors reflect the growing interest and support for examining violence and disability on a continuum from pre-victimization to victimization to post victimization. In addition, the national concern about domestic and international terrorism and the consequences for people with disabilities further prompted the sponsors to support this initiative.

In order to address the issues related to both prevention and intervention in violence and their relationship to disability, experts representing four domains of knowledge were selected as conferees. The domains include: 1. Researchers knowledgeable about violence against persons with disabilities, 2. Providers of services for people with disabilities, 3. Persons with disabilities who are themselves victims of violence or parents of victims with disabilities, and 4. Advocates for persons with disabilities. See Appendix B for the names of the conferees.

Since the intent of the Conference was to obtain the best advice and counsel from its participants, brief plenary sessions were followed by small group discussions, addressing three major questions: 1. What is the scope and magnitude of the problem? 2. What are the ways people with disabilities and their families cope with violence? 3. What steps should be taken to intervene and prevent such violence?

The small groups were divided into those who examined the needs of children with disabilities and those who focused on the needs of adults with disabilities. The groups had representatives from each of four domains listed above. Although some may suggest that the division between children and adults is arbitrary, the Conference Planning Committee (see Appendix C) believed that there were

sufficient differences in the needs of children and adults to warrant the division. The judgment of the Committee proved to be correct as evidenced by the research and clinical data that were presented at the Conference and were found in many other sources contained in this Report. The Conference Program is found in Appendix D.

This Report not only includes a summary of the National Conference, its conclusions and recommendations, but also provides more in-depth information about the broad topic of violence and disability. Conferees benefited from pre-conference materials that included Conference definitions of violence and disability (See Appendix E) and Commissioned Papers by four scholars and a bibliography (See Appendix F). In addition, five invited speakers presented information on various aspects of the Conference's theme (See Appendix G).

The Executive Summary provides a brief overview of this report and specifically lists major recommendations addressed to the Nation to end crimes of violence against children and adults with disabilities.

Chapter 1 introduces the reader to the topic of violence and disability, its definitions, and the reasons for the increased interest in the problem. Chapter 2 presents a History of Violence in America that identifies the roots and origins of violence in a society that is purported to be governed by the rule of law. Chapters 3, 4 and 5 review the major questions about the problem of violence and disability. Finally, Chapter 6 addresses the following question: Who is responsible for ending crimes of violence against children and adults with disabilities?

ACKNOWLEDGEMENTS

The Editor wishes to express her sincere appreciation to Robert J. Weber, M.D., Chair of the Department of Physical Medicine and Rehabilitation, SUNY Upstate Medical University for his support of the Conference as well as his vision and willingness to expand the boundaries of professional duty and responsibility to include issues of violence, safety and protection of children and adults with disabilities. Also, deep appreciation is extended to Margaret Turk, M.D. and Michael Marge, Ed.D. who, as Co-principal Investigators of the Conference Grant, provided advice and counsel whenever requested. Special thanks are extended to the Sponsors, including Rodney Hammond, Ph.D. and Larry Burt of CDC, Joye Whatley of the Department of Justice, Scott Brown, Ph.D. and Steven Tingus of the Department of Education, Lou Quatrano, Ph.D. of the National Institutes of Health, Patricia Morrissey, Ph.D. and Catherine Nolan of the Administration on Children and Families, Merle McPherson, M.D. of Health Resources and Services Administration, Ethel Briggs of the National Council on Disability, and Thomas Stripling of the Paralyzed Veterans of America. And, gratitude is expressed to the authors of the Commissioned Papers and Contributive Bibliography who made a significant contribution to this endeavor – Patricia Sullivan; Donald Bross; Margaret Nosek, Rosemary Hughes, Heather Taylor, Carol Howland; Nora Baladerian; Rune Simeonsson and Janie McMillen. The Editor recognizes the substantial contribution by Joan Petersilia and her associates who, by their scholarship, have advanced the cause of safety and protection of people with disabilities. Without the assistance and excellent guidance by these individuals and by the members of the Conference Planning Committee, we would not have been the beneficiaries of what has become a most successful outcome.

The Editor expresses her appreciation to Robin R.I. Nichols, Jr., MS as Production Editor of this publication for his superb advice, guidance and professional direction. Finally, she thanks Daniel J. Dippel of the SUNY Upstate Medical University Duplicating and Printing Services for his excellent cover art.

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EXECUTIVE SUMMARY

A CALL TO ACTION:

ENDING CRIMES OF VIOLENCE AGAINST CHILDREN AND ADULTS WITH DISABILITIES

This CALL TO ACTION is in response to a major crisis in the health, safety and protection of Americans with disabilities. They are at increased risk for victimization by crimes of violence and require a national program and immediate action to end the suffering, pain, and devastation many experience in their daily lives. Specifically, these consequences can include injury to the central nervous system, fractures, damage to the internal organs of the abdomen, burns, malnutrition, severe emotional and behavioral problems, and even death (Bross, 2002). In many cases, even after the physical injuries heal, the victim with disabilities continues to experience emotional trauma and associated behavioral problems.

The evidence about the crisis indicates that the problem is growing at an alarming rate. One of the most deplorable facts is that the predators who commit violence frequently are individuals who are known to the victim with disabilities and are in a position to care, protect and love. These individuals include family members, personal attendants and other caregivers, teachers, clergy, health care personnel and other authority figures. Children and adults with developmental disabilities, especially, are reported to have a high rate of victimization because of the severity and nature of their disabling condition. *The goal of this report, therefore, is to end the violence.*

Scope and Magnitude

A review of the clinical and research literature and the evidence presented at the National Conference on Preventing and Intervening in Violence against Children and Adults with Disabilities (May 2002), identified statistics that clearly highlight the greater vulnerability of persons with disabilities for victimization when compared with individuals without disabilities.

Based on the research of McNeil (1997), it is estimated that approximately 20% of the U.S. population (or 58 million Americans in 2002) have disabling conditions and represent the largest minority. Although population data that specify the scope and magnitude of the problem of victimization are limited, there are certain facts that compel all of us to address the major public problem of violent crimes against persons with disabilities. These data are:

1. A five year retrospective study of children with disabilities in a pediatric hospital found that (a) 68% of the children with disabilities were victims of sexual violence and (b) 32% were victims of physical violence (Willing et al., 1992).
2. In a retrospective study of hospital records over a ten year period with a population of 39,000, 6,000 children or 15% were victims of violence. Of the 6,000, 64% or 3,840 were children with disabilities. Over half the sample or 54% were exposed to multiple forms of violence (Sullivan & Knutson, 1998).

3. A study of 40,000 school records in the Omaha public schools during 1994 - 1995 school year revealed that 11% or 4,378 children were judged to be victims of violence. Twenty two percent were children with disabilities (Sullivan & Knutson, 2000).
4. Valenti-Hein and Schwartz (1995) indicated that 90% of people with developmental disabilities will be victimized by sexual violence at some point during their lifetime. Forty percent will experience ten or more incidents. Sobsey (1994) estimated that each year in the U.S., 15,000 to 19,000 people with developmental disabilities are raped.
5. In a study of adult women with disabilities, 62 % were victims of sexual violence and differed from women without disabilities in that they were victimized by a greater number of perpetrators and experienced a significantly longer duration of violence. Furthermore, the violence was more likely perpetrated by attendants and health providers (Nosek et al., 1997).
6. Powers et al. (in press) reported that 67% of women with disabilities experienced lifetime physical violence and 53% experienced lifetime sexual violence. These estimates are twice the rates of women without disabling conditions (National Research Council, 1996).

These data are considered the tip of the “iceberg” because what has been observed repeatedly is that victimization by violence is seriously underreported. For example, according to the Bureau of Justice Statistics (2000), only 37% of all crimes committed were reported to the police. Sexual violence, which is a stigmatizing crime, was reported even less. It was even suggested that persons with disabilities were more reluctant to report crimes of violence, especially if the perpetrator were an individual upon whom the victim depended for essential services (Tyiska, 1998).

The remaining content of this Executive Summary is a presentation of recommendations for ending violent crimes against children and adults with disabilities. The recommendations were derived from the deliberations of the National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities and from a careful review of the current literature. The recommendations fall into five critical areas: New National Policy, Surveillance and Data Collection, Violence Prevention, Intervention in Violence when it Occurs, and Research Needs.

New National Policy

The President of the United States should issue an Executive Order that –

1. Establishes a Presidential Commission on Ending Violence Against Persons with Disabilities.
2. Charges the Commission to examine the problem of violence and disability, taking into account this Report and making recommendations about ending violence against persons with disabilities to the President in eighteen months from the date of the Commission’s first meeting. The membership of the Commission should include experts in violence and disability from the following categories – researchers, advocates, consumers, service providers and policymakers. At least 50% of the membership should be people with disabilities.

3. Requires the Commission to hold regional public hearings throughout the United States (such as in ten regions) to receive data and testimony from a broad public representation.
4. Addresses topics of special concern to include (a) establishing a clearinghouse on information regarding violence and disability; (b) informing the public about proved and effective practices of prevention and intervention; (c) developing a national policy agenda; (d) developing state and local level disability programs that assure quality and accessibility to services for persons with disabilities who are victims of violence; and (e) identifying the role of the New Freedom Initiative and the Olmstead Act in a national plan for eliminating violence against persons with disabilities.
5. Outlines the elements of a National Plan to End the Violence with a timetable, budget estimate, and a list of key agents and organizations that will implement the Plan.

Surveillance Systems and Data Collection

The purposes of the following recommendations are to (a) establish a standardized and comprehensive approach to the development of a national system of data collection about violence and disability; (b) provide essential information for national planning; and (c) monitor on a regular basis the victimization status of persons with disabilities.

Recommendation 1: Include questions about persons with disabilities on all existing surveillance systems that address violence. For example, the National Violent Death Reporting System should include questions that request information about children and adults with disabilities.

Recommendation 2: Data collection efforts at the Federal level should be coordinated by an intergovernmental committee on violence and disability statistics. Membership on the new committee should include representatives from the following: National Institute on Disability and Rehabilitation Research's Interagency Committee on Disability Statistics in the US Department of Education; US Department of Health and Human Services' Office on Disability; US Department of Health and Human Services' National Center for Health Statistics, Centers for Disease Control and Prevention, Children's Bureau, and Maternal and Child Health Bureau; Bureau of Justice Statistics in the Department of Justice; the Bureau of Labor Statistics in the Department of Labor; and The Department of Veterans Affairs.

Recommendation 3: There should be standardized definitions of disability and violence.

Recommendation 4: The problem of underreporting of victimization by persons with disabilities needs to be addressed and resolved in order to obtain valid and realistic data on violence and disability. More research is required to develop valid and effective methods that will eliminate barriers to full reporting.

Recommendation 5: People with disabilities should participate at all stages and levels of development and implementation of surveys that relate to data collection about disability and violence.

Recommendation 6: Dissemination of information derived from surveys and surveillance systems should be targeted to people with disabilities as well as providers of services, policymakers, and researchers. The information should be available in accessible formats for various types of disabling conditions.

Recommendation 7: Data collection on disability and violence should request information on personal assistants, paraprofessionals, and aides and whether or not they have received anti-violence training.

Recommendation 8: Data collection efforts should examine cultural differences regarding violence against persons with disabilities. These data will be necessary to develop training programs that will assist immigrants in understanding the U.S. cultural norms about violence, in facilitating a culturally congruent approach to violence prevention, and in identifying the role of immigrants in programs for the prevention of violence.

Recommendation 9: In the development of questions for future survey research about violence and disability, researchers should seek information about the prevalence and incidence of violence as (a) the cause of the primary disability in victims and/or (b) the cause of additional health complications in victims who are already disabled.

Recommendation 10: Data collection efforts in disability and violence should identify the place where the violence occurred and the disability status of the victims. The environmental situations include but are not limited to the home, school, work, recreational facilities, streets, places of worship, residential institutions, health care settings, and transportation facilities.

Recommendation 11: Surveys should include questions about support programs, their accessibility and the attitudes and sensitivity of program personnel to the needs of individuals with disabilities who have been victimized by violence.

Violence Prevention

This category addresses the recommendations for the development and implementation of national program to prevent violence against children and adults with disabilities. Although prevention plays a significant role in ending violence against people with disabilities, it is understood that there will be individuals who may become victims despite the application of every prevention effort. In such cases, effective intervention programs for those who are victimized must be in place. It is proposed, therefore, that effective prevention and intervention programs should be developed and implemented simultaneously. The following recommendations refer to prevention efforts.

Recommendation 1: A national long-range plan for the prevention of violence against persons with disabilities should include a prevention infrastructure so that effective programs are found in each community throughout the United States. The plan should have four components: (a) establishing a Federal, state, community and schools priority for violence prevention under the leadership of a lead agency, such as the Centers for Disease Control and Prevention; (b) estimating the magnitude and scope of the problem through surveys and surveillance systems; (c) delineating goals and objectives (for reducing and/or eliminating victimization), strategies, responsible players or agents who will implement the plan, and a timetable; and (d) instituting a program, process and outcome evaluation system to monitor progress.

Under the national plan, each child and adult with disabling conditions should be trained in the basics of safety, protection, risk reduction, and prevention of violence through appropriate community-based institutions: school, work, independent living centers and places of worship. The dissemination of the basics may be reinforced through television and the internet. The training program should be accessible and sufficiently flexible to meet individual needs as well as general

group needs because research has demonstrated that persons with certain types and severity of disabling conditions require special information. In other words, “one suit does not fit all” and the program should reflect this dictum. Also, in the development of the program, people with disabilities should play a significant role in the curriculum design and implementation.

Recommendation 2: Prevention programs should be developed and applied with the following core characteristics: (a) training in violence prevention for caregivers; (b) improving the existing physical environment that will increase safety and protection of the individual (such as better lighting, alarm systems, cell phone access, buddy system, and public transportation that is monitored for safety); (c) increasing the role of law enforcement in the prevention of violence; (d) evaluating new and established programs of prevention, including appropriate self-defense skills; (e) instituting services for victims to prevent revictimization, including appropriate self-defense skills; and (f) establishing programs that teach anger-management and non-violent conflict resolution skills for children who are perpetrators as well as victims.

Recommendation 3: Increase funding to meet the cost of a national program to prevent violence against persons with disabilities. This will require Presidential and Congressional commitment and action.

Recommendation 4: Mothers and families with newborn children with disabilities should receive special instruction about the potential for victimization and ways in which to prevent such occurrences provided by instructors who are sensitive and caring.

Recommendation 5: Elementary and secondary schools should develop a policy of zero tolerance for bullying and provide violence prevention information for all children in their curricula. In addition, this information should be emphasized especially in courses that teach health education, life skills, and pre-parenting skills. Also, each community should establish an anti-bullying program as part of their anti-violence prevention effort in order to support the schools’ initiative on zero tolerance for violence.

Recommendation 6: Institutions that provide training for child care workers and baby sitters should include violence prevention information in their curriculum.

Recommendation 7: Increase awareness of the public, caregivers, family members, consumers, service providers, and representatives of professional associations about the problem of disability and violence through a coordinated campaign of public relations, education and training. Use accurate portrayals about disability and violence and assure that the information is presented in the most sensitive manner. It is essential to portray people with disabilities as people first and then people with disabilities next.

Recommendation 8: Include persons with disabilities in existing and future anti-violence campaigns.

Recommendation 9: The US Department of Homeland Security should incorporate in its national plans for the safety and protection of the American people, the special needs of children and adults with disabilities.

Recommendation 10: The national prevention program to end violence against persons with disabilities should work in collaboration with the criminal justice system and organizations and agencies at the national, state, and local levels, including the National Crime Prevention Council.

Recommendation 11: Train all foster families with children with disabilities about violence prevention and disability and their role in preventing crimes of violence. In addition, identify effective ways for foster parents to access advocacy whenever necessary.

Recommendation 12: Training in preventing violence against persons with disabilities should be included in the pre-service and in-service curriculums of all professionals who provide human services to include teachers, social workers, psychologists, physicians, allied health professionals, and law enforcement personnel. The curriculums should cover information about disability issues, specifically the provisions of the Americans with Disabilities Act.

Recommendation 13: Perform background checks on all non-family personnel who will be caring for children and adults with disabilities.

Recommendation 14: Add the following new objective in Chapter 6: Disability and Secondary Conditions in Healthy People 2010:

Objective 6.14: By 2010, 50% of the communities in the United States will establish a violence prevention coalition for the purpose of ending crimes of violence against persons with disabilities.

Intervention in Violence when it Occurs

The recommendations listed below refer to programs and activities that will provide the best quality services for people with disabilities who become victims of crimes of violence.

Recommendation 1: Each community should establish a working coalition comprised of key representatives from pertinent agencies and organizations that contribute to the care and recovery of persons with disabilities who have become victims of crimes of violence. The coalition should address the three phases of Intervention: Phase One-acute and emergency care; Phase Two-the recovery period; and Phase Three-training, rehabilitation and prevention of revictimization. Phase One will include first responders, emergency medical personnel, firefighters, law enforcement personnel, family members, and advocates. Phase Two will include medical service providers for ongoing medical care, counselors, social workers, family members, and advocates. Phase Three includes medical personnel, trainers in safety, protection and the prevention of revictimization, family members and advocates.

The coalition will inform all of its representatives and personnel about the needs of persons with disabilities. These factors include instituting appropriate programs of intervention for the special needs of people with disabilities and demonstrating positive attitudes and sensitivity in managing people with disabilities who have been victimized. The providers of services must correct their attitudinal biases toward people with disabilities and change their beliefs in myths and stereotypes that defeat efforts to institute a positive program of intervention (Baladerian, 2002). Also, the coalition will assure that all services will be accessible and that emergency services will be available 24 hours per day, 7 days per week. In addition, people with disabilities who have been victimized will have available

personnel assistance services, transportation, appropriate housing and equipment suitable for persons with disabilities.

Each coalition should establish an evaluation component and a data collection system.

Recommendation 2: The US Department of Justice and the Office for Victims of Crime should require that all recipients of their funds for support of services for victims of crime must provide accessible services according to the terms of the Americans with Disabilities Act.

Recommendation 3: The US Department of Health and Human Services and the Department of Veterans Affairs should require that recipients of funds for health services delivery, such as support for emergency medical services, must provide accessible services under the terms of the Americans with Disabilities Act.

Recommendation 4: Through the effort of the Governor's office of the advocate on disability, each state that provides support for services for victims of crimes of violence must comply with the terms of the Americans with Disabilities Act. Accessibility of services for victims of crimes of violence should extend to each community within the state.

Recommendation 5: The Rehabilitation Services Administration should provide funding to train staff at centers for independent living on violence and disability issues.

Recommendation 6: The criminal justice system in the United States at the Federal, state, and local levels needs to immediately modify its approach and practices to address the requirements of people with disabilities who have become victims of crimes of violence. In concurrence with the information and suggestions by Petersilia et al. (2001), Tyiska (1998) and the additional suggestions by the conferees at the National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities, the following changes in the criminal justice system are proposed:

- a. Each community should have trained advocates and attorneys who assist victims with disabilities to navigate the criminal justice system.
- b. An advocate and attorney assigned to meet the needs of a victim should remain with the victim throughout the criminal justice process. These services are perceived as "vertical supports."
- c. Alleged perpetrators of crimes who are persons with disabilities should be assigned advocates and attorneys who are trained on matters of disability.
- d. All personnel in the criminal justice system, including law enforcement and corrections personnel, should receive training on disability issues.
- e. The Victim Assistance field needs training on disability issues. This is referred to as "horizontal supports" for people with disabilities as they move across agencies for services.
- f. It has been reported that victims with disabilities, especially those with cognitive and mental health disorders, may not have been afforded the full benefits of due process in criminal cases. The criminal justice system must guarantee that in the future persons with disabilities who are victims of crimes of violence are provided a full measure of due process under the law.

- g. The Hate Crime Law should be amended to include crimes against persons with disabilities along with other protected classes. Since the current Law covers only certain situations and places, this Law should be amended to include crimes against people with disabilities under any circumstance and in any location.
- h. Future laws regarding protected classes must also include persons with disabilities as a category.
- i. All police and sheriff departments, regardless of size, should have a coordinator for the application of the provisions of the Americans with Disabilities Act (ADA), who is fully knowledgeable about the ADA, and is responsible for its implementation in everyday law enforcement activities.

Recommendation 7: For improved accessibility and efficiency, each state should develop a victim’s coordinating committee for funding programs and services that assist victims with disabilities.

Recommendation 8: The Federal and state programs for victim’s assistance should partner with non-profit organizations as a means to increase resources and coordinate national efforts to assist victims of violence.

Recommendation 9: A comprehensive perspective of disability and violence must include the expanding social fabric of the United States. As people immigrate from other cultures, especially those with disabilities, there is a need to provide them with services that overcome the barriers of status, language, and culture.

Research Needs

In addition to the gaps in existing population databases about the scope and magnitude of the problems of violence and disability, many observers have identified areas of needed research. Questions have been raised about causes of violence, characteristics of perpetrators, and efficient and cost effective approaches to prevention and intervention for persons with disabilities who are victims of crimes of violence. The recommendations which follow were proposed by researchers, advocates, consumers, and providers of services and represent a current perspective for the development of a research agenda.

Recommendation 1: Research is needed in understanding the victim/perpetrator relationship as one important factor in developing effective programs for the prevention of victimization and revictimization.

Recommendation 2: Address the research question: “To what extent does the disability status of children and adults impact on the recognition, reporting, and response to violence when the victim is identified and interviewed?”

Recommendation 3: Study the research question: “How can we improve recognition of victimization by violence in children and adults with severe communication problems?”

Recommendation 4: Study children with disabilities who are physically and/or sexually aggressive toward other children in order to understand and develop programs of violence prevention.

Recommendation 5: Conduct a longitudinal study on children and adults with disabilities and their families that assesses perceptions and experiences with service programs before and after victimization.

Recommendation 6: Inventory existing research information about risk and protective factors as they relate to violence against people with disabilities. Include

information about the environment, such as home, school, work, service agencies and community, as a factor in increased risk for victimization.

Recommendation 7: Study the cultural differences of perceptions and responses to various types of acts of violence against persons with and without disabilities.

Recommendation 8: Conduct research on the prevalence, incidence, and causes of violence against persons with disabilities and develop effective prevention strategies.

Recommendation 9: Study the impact of self-defense training on the self-image and feelings of empowerment of persons with disabilities.

Recommendation 10: All research on issues related to disability should identify types of disabling conditions under study.

Recommendation 11: Request that the National Institute on Disability and Rehabilitation Research include in its electronic communication to researchers, consumers, providers, and others, summaries of research findings pertinent to disability and violence and continuous updates of these reports.

Recommendation 12: Conduct a longitudinal study on children with disabilities and research why some children are more resilient and recover more quickly than others when both are victimized by violence.

Recommendation 13: Conduct systematic evaluations of the impact of state mandatory reporting laws on the reports of state incident levels of crimes of violence against persons with disabilities.

Recommendation 14: Address the question of the relationships between the risk factors and consequences of disability status, conduct well-controlled methodological studies that compare (a) the type of violence against children with genetically caused disabilities and (b) type of violence against children with acquired disabilities and (c) compare these groups with types of violence directed toward children without disabilities.

Recommendation 15: Conduct studies on the role of aggressive and anti-social behavior in the increased risk for victimization. In other words, the undesirable behavior may covary as a function of violence and disability status (Sullivan, 2002). Children with disabilities who exhibit physically and/or sexually aggressive behavior and anti-social behavior may be at greater risk for victimization.

Recommendation 16: Conduct randomized controlled trials of interventions for victims of violence with disabilities with multi-year follow up to determine effectiveness in improving outcomes and to identify risk factors for violence (Nosek et al., 2002).

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CHAPTER ONE:

INTRODUCTION TO VIOLENCE AND DISABILITY

Significance of the Problem

Only during the past fifteen years have people with disabilities become a major focus of the U.S. public health system (M. Marge, CF*, 2002). There are three significant reasons for this focus. First, researchers and policymakers are just becoming aware of the magnitude of the population of people with disabilities. Based on McNeil's (1997) estimates projected to the year 2000, there are 58 million Americans with disabilities or approximately 20% of the U.S. population. People with disabilities are now the largest minority population in America. Second, the cost of health care for people with disabilities is extraordinary and needs to be promptly addressed. The direct medical and indirect annual costs for health care for 1999 were approximately \$740 billion. Costs associated with disability were more than \$350 billion. The total cost includes approximately \$165 billion in medical care expenditures and \$185 billion in lost productivity costs. Twenty percent of the population, therefore, requires almost 50% of the health care budget (Max, et al., 1996). A third reason is that there are major disparities in the health care, wellness, and safety of people with disabilities who are at risk for additional health complications, including the acquisition of secondary conditions (M. Marge, CR, 2002). Included in this category of care is increased risk for becoming a victim of crimes of violence (M. Marge, 1995).

Children and adults with disabilities are at considerable risk for violence by caregivers, caretakers (such as personal attendants) and other persons who are known to the individual. Although less frequent, people with disabilities may become victimized by perpetrators who are unknown to them, such as criminals who execute acts of violence on a random basis.

It will be described later in this chapter that those at greatest risk are persons with types and severity of disability that limit the ability for self-protection. Four major self-protective abilities include (1) the ability to comprehend danger to self; (2) the ability to escape from the perpetrator or, as some describe, the protective ability for flight from danger; (3) the ability to fend off the perpetrator when physically assaulted; and (4) the ability to communicate to law enforcement the nature of the crime. Persons with severe disabilities that reduce function in cognition and intellectual capacity, vision and hearing, speech and language, walking and running, and physical strength in the hands, arms, torso and legs, are at greater risk than those with slight or without disabling conditions.

There are unique issues related to crime victims with disabilities. According to Tyiska (1998), they are associated with the following problems: (1) underreporting of crimes, (2) lack of responsiveness from law enforcement or prosecutors who question the credibility of the victim, (3) increased possibility of repeated victimization, (4) lack of effective, accessible and disability appropriate services, (5) physical or social isolation of the victim, and (6) a judicial system that is centered on the rights and needs of the offender and not the victim. In addition to these general problems, other special issues include that people with disabilities often do not have resources and the physical stamina to cope with the

*CR means "conference remarks" made by conferees during the National Conference on Preventing and Intervening in Violence against Children and Adults with Disabilities," May 6 and 7, 2002.

delays and hurdles of the criminal justice system. Some victims who are parents face the prospect of losing custody of a child because the courts may decide to assign custody to a non-disabled perpetrator/partner in a domestic violence case.

Operational Definitions of Violence and Disability

For the purposes of this Report, the definition of violence and the definition of disability used for the Conference on May 6 - 7, 2002 (Appendix F) have been modified. Based on subsequent data, the Operational Definitions used for this Report reflect notable changes and elaborate on issues that relate to the general public as well as individuals with disabilities who face possible victimization by crimes of violence.

The new operational definition of violence focuses on the acts of violence and their *gravity*, identifying these acts as serious crimes, punishable by law. It will be pointed that criminal acts of violence include not only homicide, rape, sexual assault, robbery, aggravated assault, theft, and burglary, but also acts of torture that encompass threats of death, severe physical pain or suffering, or severe mental pain or suffering, harassment and stalking.

Previous definitions of disability do not address the degree of risk of individuals with disabilities for possible victimization or revictimization by crimes of violence. It will be shown that the new operational definition of disability includes the factor of degree of risk because it is a necessary factor in understanding the relationship between disability and violence.

Definition of Violence for Purposes of this Report

A crime of violence is a harmful act (offense) that involves the use, attempted use, or threatened use of physical force committed by a perpetrator(s) against persons with disabilities that will lead to physical and/or mental injury or death.

*** This section on Definition of violence was authored by D. K. Marge, Ph.D. (2002)**

Because we live in a country that follows the rule of law, “criminal law sets the acceptable limits of conduct in society. Everyone is expected to obey the criminal law under penalty of punishment. The criminal law generally does not require you to perform an action; rather it *forbids an unlawful action*. Each state and the Federal government has its own set of criminal laws” (Legal Consumer Guide, 2003).

The United States Code (United States Congress, 2000), a database prepared and published by the Office of the Law Revision Counsel, U.S. House of Representatives, contains the general and permanent laws of the United States. Title 18, Part I identifies the types of violent acts that are considered crimes against persons. They include, but are not limited to, the following: homicide, sexual abuse, sexual exploitation and other abuses of children, domestic violence and stalking, torture, terrorism, kidnapping, malicious mischief, obscenity, peonage and slavery, and conspiracy against rights (Legal Information Institute, 2003).

In addition to Federal crimes, there are also state and local laws that identify crimes unique to their jurisdiction. The Federal Bureau of Investigation (FBI) identified the use of a data collection system (NIBRS) that reports information to the Uniform Crime Report Program. The National Incident-based Reporting System (NIBRS) “collects data on each single incident and arrest within 22 offense categories made up of 46 specific crimes called Group A offenses. For

each of the offenses coming to the attention of law enforcement, specified types of facts about each crime are collected. In addition to the Group A offenses, there are 11 Group B offense categories for which only arrest data are reported.” Crimes of violence that are identified in Group A category and are specific to our concern include: Assault Offenses – Aggravated Assault, Simple Assault, Intimidation; Homicide Offenses – Murder and Nonnegligent Manslaughter, Negligent Manslaughter, Justifiable Homicide; Kidnapping/Abduction; Pornography/Obscene Material; Prostitution Offenses—Prostitution, Assisting or Promoting Prostitution; Robbery; Sex Offenses, Forcible—Forcible Rape, Forcible Sodomy, Sexual Assault With An Object, Forcible Fondling; and Sex Offenses, Nonforcible—Incest, Statutory Rape. The following offenses from the Group B category are specific to our concern and include: Disorderly Conduct; Drunkenness; Family Offenses, Nonviolent; Peeping Tom; Runaway; and Trespass of Real Property (Federal Bureau of Investigation, 2003).

The FBI’s Uniform Crime Report (UCR) is “compiled from monthly reports transmitted to the FBI from law enforcement agencies across the country, either directly or through centralized state agencies . . . The crimes selected for inclusion in the UCR Program were chosen because they were considered both serious offenses and likely to be *reported* to the police,” according to Rand and Rennison (2002). These reported crimes include homicide, rape, robbery, aggravated assault, theft, burglary, motor vehicle theft and arson.

On the other hand, the National Crime Victimization Survey (NCVS) of the US Department of Justice, “measures crimes that people experienced, *whether or not reported to police*,” Rand and Rennison continued. Crimes measured by the NCVS include rape/sexual assault, robbery, aggravated assault, simple assault, theft, burglary and motor vehicle theft.

It has been implied that in order for an act of violence to be considered a crime of violence, a law must be in place that the act of violence has violated. The aforementioned selected references (United States Code, Title 18, Part I; National Incident-based Reporting System; Uniform Crime Report; and National Crime Victimization Survey) clearly identify behaviors that are criminal and violate laws in the United States.

These crimes may occur in any situation in which persons with disabilities are victimized by family members, friends, caregivers, teachers, religious personnel, service providers and strangers. Victimization of persons with disabilities is of particular concern because of (a) the extensive reports of their degree of risk; (b) lack of public awareness of the problem; (c) concealment and acceptance of these crimes of violence; and (d) the need for protection, safety and accessible services that are effective and sensitive to the requirements of those who have become victims.

Although much has been written and studied about children and adults in the general population who have been victims of violence, children and adults with disabilities have been overlooked. For some reason, perhaps lack of awareness, the general public has ignored the impact of violent crimes on persons with disabilities. Baladerian (2002) reported that children with disabilities are not perceived as possibly being victims of child abuse, neglect and maltreatment. Although there have been some recent studies of violence against women with disabilities, particularly domestic violence, for the most part the public perceives that persons with disabilities do not have partners or sex lives. And, we should

not overlook the fact that men with disabilities are also victims of violence. In a “macho” culture where men are reluctant to admit to victimization, it is still important to identify problems that men with disabilities face. Lee et al. (2002) expressed the need to study the impact of violence against persons of color but the study should be expanded to include violence against persons of color who have disabilities.

Crimes of violence, both intentional and unintentional, may occur to persons with or without disabilities regardless of age, gender, race, sexual orientation, religion or other characteristics. Criminal acts of violence may be perpetrated in environments that include the home, school, church, community and work. Violence is found in environments that include the home, school, church, community and work. Recent reports of violent behavior have been identified in some, heretofore, unexpected environments. For example, incidents of road rage, air rage, parking lot rage, and parental rage at children’s athletic events have escalated in violence to the point of severe injuries or death to victims of these attacks. Sexual crimes of violence against children, for example, have occurred in day care centers by caregivers, in schools by teachers or other authority figures, in religious facilities by clergy or other religious personnel, in camps by counselors, in health care settings by health care providers as well as in other institutions where the safety and care for dependent persons have been entrusted and, formerly would never be questioned. School safety, aside from the problems of pedophilia or paraphelia, is now an environment for contemporary concern where children may seek “revenge” by using deadly force (bombs and guns) and killing their tormentors, those whom they perceived as having teased, bullied, humiliated, excluded and dehumanized them. For these child perpetrators, access to weapons is easily available to commit these crimes and other weapon-related acts.

One of the consequences of experiencing or witnessing acts of violence, is the acquisition of post traumatic stress disorder (PTSD). Because of the recent attacks on the United States by terrorists, acts of violence against individuals now include both personal crimes of violence as well as injuries and death resulting from domestic and international terrorism. Terrorism is defined by the Department of Defense as “the calculated use of violence or the threat of violence to inculcate fear; intended to coerce or to intimidate governments or societies in the pursuit of goals that are generally political, religious, or ideological” (Terrorism Research Center, 2002). Once considered a dreaded experience that occurs to persons in other countries, these crimes of violence now have come to our shores along with concerns about anthrax and other biological and chemical agents that could be used as weapons against the American population. Post traumatic stress disorder is no longer a condition that is confined to terrorism or government sanctioned violence (war). It is identified as a possible consequence of witnessing or experiencing “non-war” related acts of violence which has been reported in the lives of persons with disabilities.

It is assumed that violent crimes take place between the victim and the perpetrator in isolation, but this is not necessarily the case. Although current studies of third parties do not specifically identify people with disabilities, one can assume that the data apply equally to those with and without disabilities. Planty (2002) reported that frequently crimes of violence may involve a third party who becomes a witness or another victim, or even intervenes to assist the primary victim or to stop the crime. Planty also found that third parties were

present at two-thirds of all criminal victimizations from 1993 – 1999. They were involved in (a) 70% of assaults, (b) 52% of robberies, and (c) 29% of rapes or sexual assaults.

Hate crimes and their violent results are currently the subject of interest for many researchers. Persons who do not conform to the “organizational perception” of acceptability by hate groups may be targeted for violence (Dees, 1996). It has been reported that persons with disabilities have been targets for hate crimes (C. Decker, Personal Communication, January 10, 2003). Efforts are underway to include persons with disabilities as a category of potential victims in an amendment to the Hate Crime Act.

The technological advances in the United States have a “downside” with the use of computers for cyberstalking and harassment. Perpetrators, using chat rooms, could bait and lure persons to environments where crimes of violence could be committed, and where the growth of the pornography industry provides easy access to child pornography and other forms of degradation for pedophiles and paraphiles.

Furthermore, persons with disabilities who experience crimes of violence are not the only victims. There are “secondary victims” as well, to include parents, siblings, and other family members or caregivers of the victims. They may experience stress, anxiety and fear for the safety and life of the victims as well as their own.

If we seriously wish to address the problem of violence in America, it will require a one-on-one change in interpersonal behavior where we respect one another and seek peaceful conflict resolution to the current and future problems we face in a complex and global society. The methodology of non-violent conflict resolution in addition to respect for human dignity must be given the highest priority in our daily living (D. Marge, 1996).

Definition of Disability for Purposes of this Report *

In the context of the topic of disability and violence, individuals with disabilities are those who have chronic physical and/or mental functional limitations that (a) reduce their capacity for self-protection and prevention and thereby (b) increase their risk for victimization by crimes of violence, especially if they are placed in certain potentially violence-generating situations.

***This section on Definition of disability was authored by M. Marge, Ed.D. (2003).**

The definition implies that there is need for special safety and protective measures so that the individual may realize an equally substantial reduction in degree of risk and, therefore, avoid victimization. Also, the definition implies that certain situations should be addressed as potentially dangerous for individuals with limitations. The search for a definition of disability that is politically correct, meaningful and utilitarian has been difficult and challenging. In an ideal world, the differences in individuals should be perceived as matter of fact and a reflection of nature. Some would prefer that the differences are accepted even more positively as evidence of the uniqueness of each individual. The insightful student of history will recognize, however, that American society’s perception about disability is in a period of transition from (a) one that previously assessed the differences as deficits, deviations from the norm, and demeaning to (b) the current

one that protects the rights of each individual from discrimination, provides public-sponsored programs to accommodate the needs of persons with disabilities, and raises the sensitivity and awareness about the importance of accepting differences as an expected norm. This author predicts that before the end of the century the term *disability* will no longer be culturally or socially appropriate (as contrasted with politically acceptable) and individuals will be referenced by their name without any further qualifications – a world that accepts and appreciates the differences in others and interacts with an individual’s strengths and not their weaknesses. This will be a world that provides the essential services and programs to assist *each* individual to realize the greatest degree of independence and well being.

During the past four decades a number of important developments have transformed the definition of disability from one that focused on the health condition of the individual to the current definitions that address the interactions between the individual and the environment. Some of these important developments included the Rehabilitation Act and its subsequent amendments, the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act, the World Health Organization’s International Classification of Functioning, Disability and Health, the growth of politically active advocacy groups (such as the Consortium for Citizens with Disabilities), and the emergence of nationally recognized leaders with disabilities or who have family members with disabilities. Among the thousands who have significantly contributed to one of the greatest revolutions in American life and culture, this author recognizes those who have provided inspiration and leadership: Irving Kenneth Zola, Justin Dart, Jr., Joe Dusenbury, U.S. Senator Tom Harkin, U.S. Senator Bob Dole, U.S. Senator Ted Kennedy, U.S. Congressman Silvio O. Conte, U.S. Congressman Henry Waxman, Lex Frieden, Margaret Nosek, Bob Williams, David Gray, Paul Hearne, Judy Heumann, Marca Bristo, Katharine Seelman, Becky Ogle, Steven J. Tingus, John Hager, Andrew Batavia, Pat Morrissey, Margaret Giannini, and Larry Burt.

A survey of Federal statutory definitions of disability conducted on behalf of the National Institute on Disability and Rehabilitation Research (Domzal, 1995) reveals that there are 50 acts and programs with their own definition of disability. It underscores one of the purposes of these definitions providing a rubric for the distribution of support or services for each agency. For example, the Social Security Administration’s definition of disability states, “To be considered disabled under either the Disability Insurance or the SSI program, a person must be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that has lasted or is expected to last 12 months or to result in death. An individual’s physical or mental impairment(s) must be of such severity that he is not only unable to do his previous work but cannot, considering his age, education and work experience, engage in any kind of substantial gainful activity which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work” (Social Security Administration, 2002).

The ADA’s Statutory Definition (The U.S. Equal Employment Opportunity Commission, 2001) is as follows: With respect to an individual, the term “disability” means (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment. A person must

meet the requirements of at least one of these three criteria to be an individual with a disability under the Act. The first part of the definition covers persons who actually have physical or mental impairments that substantially limit one or more major life activities. The focus under the first part is on the individual, to determine if (s)he has a substantially limiting impairment. To fall under the first part of the definition, a person must establish three elements: (1) that (s)he has a physical or mental impairment (2) that substantially limits (3) one or more major life activities. The second and third parts of the definition cover persons who may not have an impairment that substantially limits a major life activity but who have a history of, or have been misclassified as having, such a substantially limiting impairment, or who are perceived as having such a substantially limiting impairment. The focus under the second and third parts is on the reactions of other persons to a history of an impairment or to a perceived impairment. A history or perception of an impairment that substantially limits a major life activity is a “disability.” These parts of the definition reflect a recognition by Congress that stereotyped assumptions about what constitutes a disability and unfounded concerns about the limitations of individuals with disabilities form major discriminatory barriers, not only to those persons presently disabled, but also to those persons either previously disabled, misclassified as previously disabled, or mistakenly perceived to be disabled. To combat the effects of these prevalent misperceptions, the definition of an individual with a disability precludes discrimination against persons who are treated as if they have a substantially limiting impairment, even if in fact they have no such current incapacity.”

In comparison with the definition of the ADA, the SSA definition is very strict and excludes many individuals who either perceive themselves or are perceived by others to be disabled.

Conceptual Considerations

Since the focus of this Report is on people with disabilities and crimes of violence, it is necessary to examine the specific problems and issues that relate to the prevention of violence and the effective interventions required in the event of victimization. At this point, several concepts should be introduced and discussed. They are Hazards, Degree of Risk, Vulnerability, Safety and Protective Measures, and Situations that may promote victimization.

Hazard: A hazard is an act or event that will cause serious physical and/or mental injury to a person or persons. It may take the form of a climatic disaster, such as an earthquake or flood, a criminal act where a perpetrator physically assaults another individual, or an unexpected fall from a ski lift that results in serious injury or death.

Degree of Risk: In the context of crimes of violence, this refers to the probability that a person with a disability may become victimized. The term is borrowed from the field of public health where it is used to assess the various degrees of risk by individuals who face a variety of potential health hazards. For example, people who live within a three mile radius of the San Andreas fault in California are at higher risk for property damage and physical injury from frequent earthquakes than those who live in an area 1,000 miles east of the fault where earthquakes are rare.

The degree of risk for an individual is related to four factors: (a) the potential for morbidity and fatality of the hazard caused by another person or persons (e.g., criminals), devices (e.g., weapons, automobiles), and the environment

(e.g., teratogens, earthquakes, floods, and fires); (b) the level of an individual's prevention orientation (preparedness) reflected in the personal choices she or he makes in everyday life activities; (c) capacity of an individual to successfully avoid physical and mental harm when faced with an unexpected hazard; and (d) the existence of systems that protect and support an individual in the event of a hazardous occurrence.

Vulnerability: Degree of risk is oftentimes used synonymously with vulnerability. The terms have somewhat different meanings. Degree of risk refers to a measure of potential victimization whereas vulnerability implies that an individual is truly at high risk for victimization because she or he does not have (a) the protective attitudes, (b) prevention orientation, (c) physical and/or mental functional capacity, and (d) protective support systems to prevent exposure to a hazard. Or, when confronted with a hazard, the individual is unable to successfully avoid victimization. Curiously, the term "vulnerability" has created debates about its appropriateness at a time in the history of changing political and cultural attitudes concerning people with disabilities. To some, vulnerability is an appropriate public health term to mean that an individual or a segment of the population is particularly at greater risk for morbidity or fatality. To others, especially some in the disability advocacy movement, it is a derisive term if it is applied to people with disabilities because it is considered demeaning and implies weakness and helplessness. For the purposes of the definition of disability in the context of violence, the term "vulnerability" will not be used in this Report. In reference to actual or potential degree of exposure to crimes of violence, the term "degree of risk" will be used.

Many individuals with and without disabling conditions have the capability to avoid dangerous exposures to violence (relatively low degree of risk for exposure and victimization) and if confronted with a potentially violent situation have the ability to escape or protect themselves from harm. According to the circumstance, despite all the capabilities and coping behavior, it is possible that an individual may be unsuccessful and realize serious harm or death. Persons with disabilities who may have limitations in mental or physical function, such as vision, hearing, talking, walking and running, may be at greater risk for serious harm or death. Figure 1: (See page # 11) lists some of the types of disabling conditions that have been reported at increased risk for victimization.

For example, a person who is blind or uses a wheelchair and finds herself or himself in an isolated situation with a perpetrator is seriously compromised in terms of escape or personal protection. A colleague who uses a wheelchair and lives on the West Side in Manhattan informed this author that he needs to know the cost of the "fix" for the day in order to carry enough cash to deter the potential attacks of drug users. A thief may confront him with a demand for money even in the presence of others. Some thieves have threatened to push his wheelchair into the path of an auto or force him out of his wheelchair if they did not receive money.

Safety and Protective Measures: refer to the programs and services required to reduce the degree of risk for becoming a victim of violence or if victimized, refers to programs and services necessary for preventing revictimization. The activities include the following: (a) provision of assistive technology to increase the capacity necessary for independent living; (b)

provision of training on how to prevent victimization; (c) as needed, provision of a personal assistant or companion for purposes of protection and safety; (d) independent and objective monitoring of children with disabilities in foster homes and institutions by a case manager with public authority (to prevent crimes of violence against children); (e) provision of attentive, sensitive and effective law enforcement for safety in places where people with disabilities reside, work and recreate; (f) effective, accessible, sensitive, and prompt law enforcement and health services for crisis intervention when a person with a disability is victimized; (g) effective and accessible counseling for mental health (e.g. for post traumatic stress disorder) and safety and protection training for victims of crime to prevent revictimization; and (h) active and accessible community-based programs to reduce and prevent crime through law enforcement, the courts and citizen action groups.

Situations that may increase exposure to hazards: refers to the physical circumstances, the expected behaviors of individuals within the physical circumstances, and interaction with the child or adult with disabilities. The following situations have been identified where people with disabilities have become victims of crimes:

- a. Children and adults in institutions for the disabled;
- b. Infants and children at home with caregivers and parents;
- c. Seriously debilitated adults with personal assistants;
- d. The elderly with disabilities in nursing homes; and
- e. Children and adults on the streets in inner cities.

Figures 2 and 3 (See pages # 12 and 13) describe the personal characteristics and environmental factors that result in a High Risk Mode, potentially leading to victimization and revictimization. The items listed represent some of the most significant factors as reported in the clinical and research literature.

In contrast, Figures 4 and 5 (See pages # 14 and 15) identify the personal characteristics and environmental factors that result in a Prevention Mode with a more desirable outcome. Again, these items were derived from the clinical and research literature about the most effective ways to prevent the exposure to crimes of violence.

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Figure 1:
Who is at Greatest Risk for Victimization by Crimes of Violence?
Partial List of Conditions at Risk

Category of Disability	Reasons
1. Severe disorders of speech, language and cognition associated with: <ul style="list-style-type: none"> • Traumatic brain injury • Intellectual deficit • Cerebral vascular accidents (aphasias) • Dementia • Autism 	Individual has diminished ability to comprehend, reason, or communicate. Increases risk for victimization because many perpetrators seek individuals who are unable to understand and communicate criminal actions and whose credibility will be questioned because of the disability.
2. Psychopathology, including severe: <ul style="list-style-type: none"> • Schizophrenia • Bi-polar mental disorder • Clinical depression 	Similar to those with cognitive disorders, individuals with psychological problems are readily victimized because the perpetrator can raise questions about credibility of the accuser.
3. Physical Disorders, including severe: <ul style="list-style-type: none"> • Cerebral palsy • Muscular dystrophy • Multiple sclerosis • Spinal cord injury • Spina bifida • Post-polio • Atrophic lateral sclerosis • Advanced respiratory disease • Serious cardiovascular disease (e.g. heart disease) 	Although some of these conditions may involve compromised speech and language abilities, the key problem is the ability of the individual to physically escape from the location where violence may be or is occurring and is able to fight back against a perpetrator. Disabilities in this category usually result in loss of strength of the large muscle groups and reduce the individual's chance of defending themselves against physical assault.
4. Sensory Disorders, including: <ul style="list-style-type: none"> • Blindness • Deafness • Deaf-blind 	Individuals who are blind and those who are deaf-blind will have a reduced sense of danger as well as an inability to escape from a dangerous encounter. Those who are deaf will have diminished ability to sense danger but are usually physically capable of defending themselves against physical assault or escaping a dangerous situation.

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Figure 2.

Factors Related to Degree of Risk for Victimization of Persons with Disabilities

Potential Exposure to Existing Hazards: Street Violence, Domestic Violence, School Violence, Workplace Violence, Violence in Other Environments (e.g., churches, recreational clubs, dating)

HIGH RISK MODE:

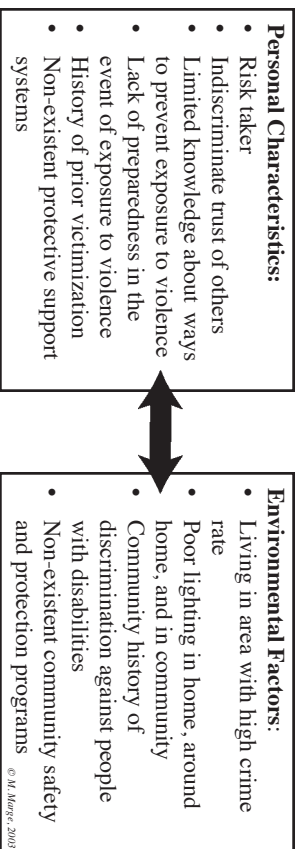


Figure 3. Progression Toward Victimization and Revictimization of a Person with a Disability

Potential Exposure to Existing Hazards: Street Violence, Domestic Violence, School Violence, Workplace Violence, Violence in Other Environments (e.g. churches, recreational clubs, dating)

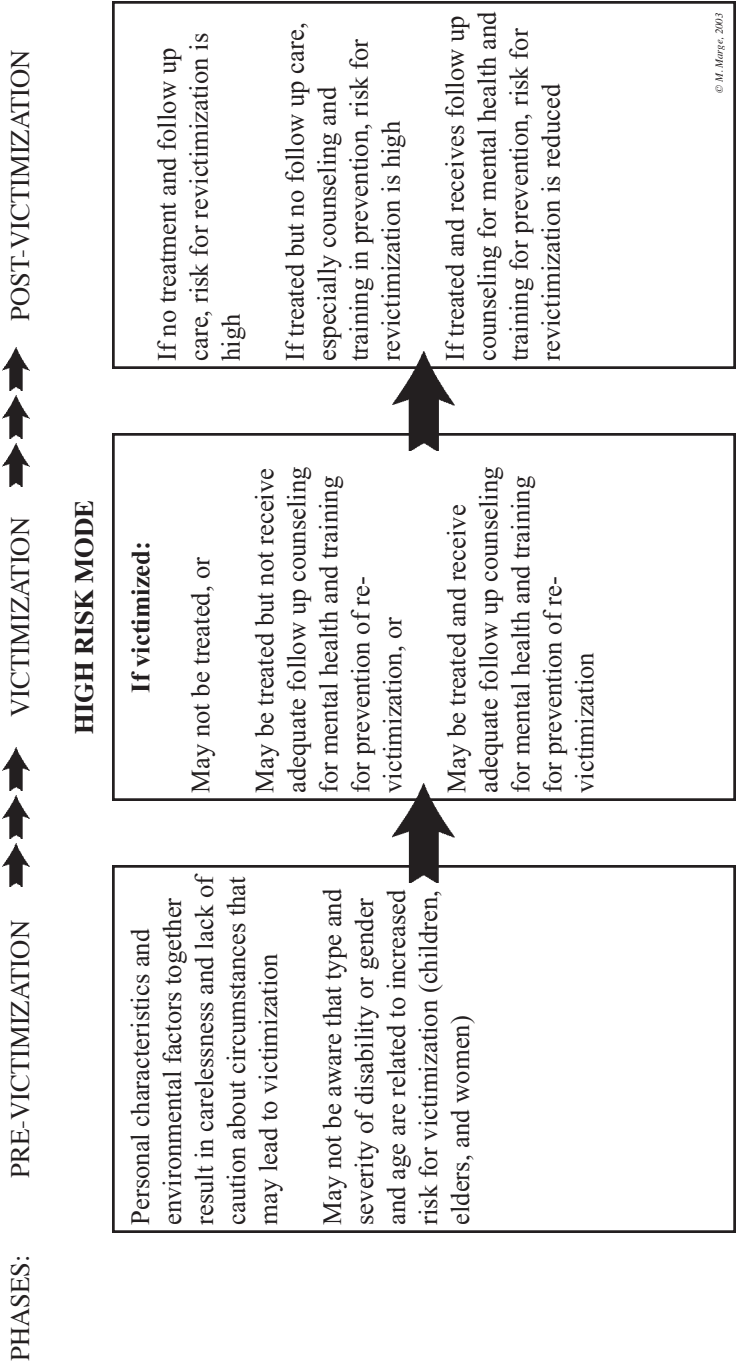


Figure 4.

Factors Related to Degree of Risk for Victimization of Persons with Disabilities

Potential Exposure to Existing Hazards: Street Violence, Domestic Violence, School Violence, Workplace Violence, Violence in Other Environments (e.g., churches, recreational clubs, dating)

PREVENTION MODE:

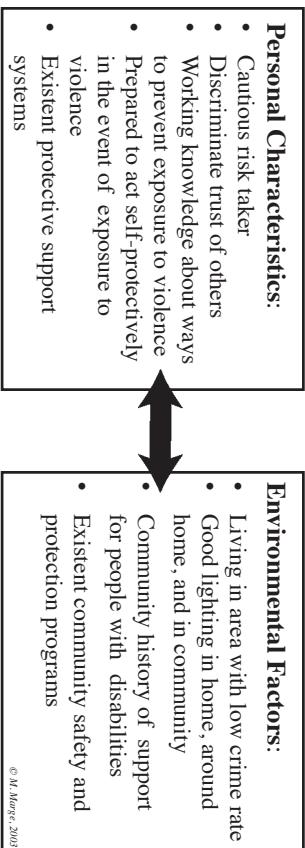
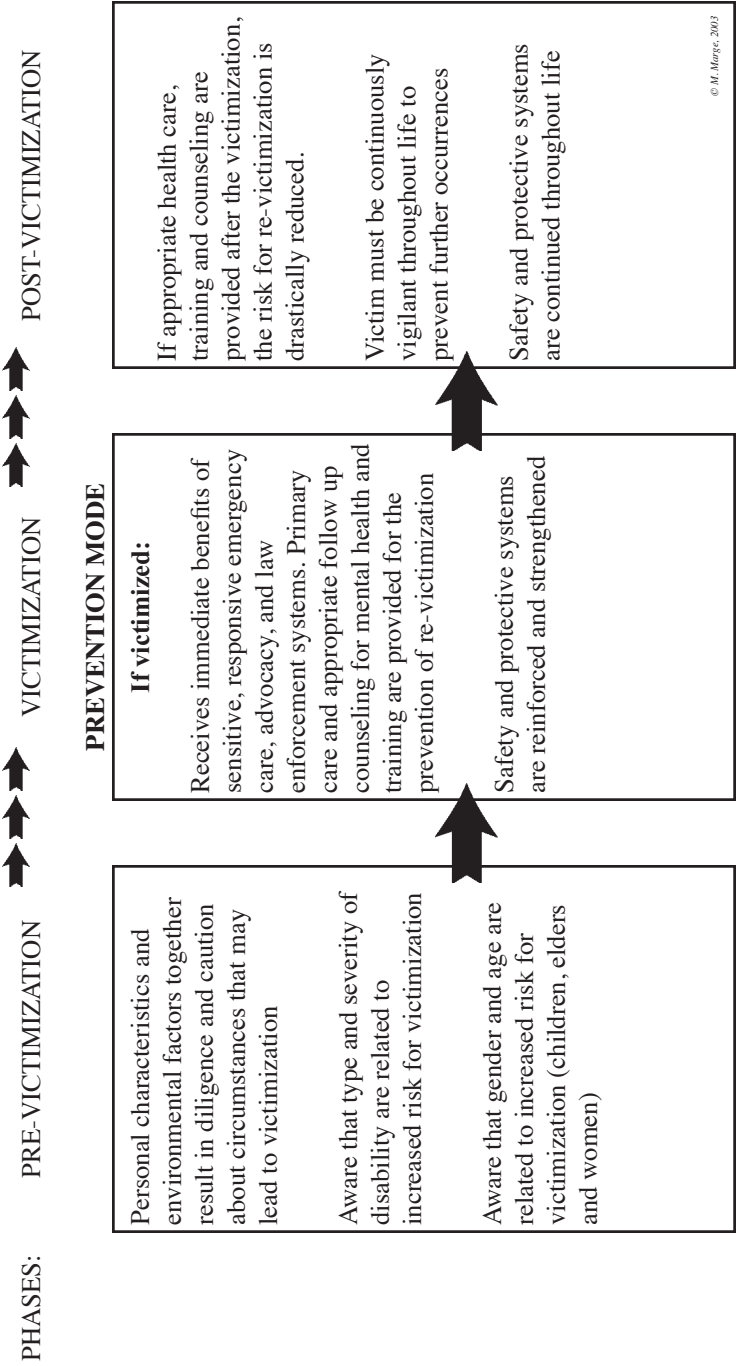


Figure 5. Prevention of Victimization and Revictimization of a Person with a Disability Potential Exposure to Existing Hazards: Street Violence, Domestic Violence, School Violence, Workplace Violence, Violence in Other Environments (e.g. churches, recreational clubs, dating)



CHAPTER TWO: VIOLENCE IN AMERICA – A REVIEW OF HISTORICAL AND CONTEMPORARY FACTORS

Dorothy K. Marge, Ph.D. (2003)

In order to develop and implement effective programs for the prevention of violent crimes against children and adults with disabilities, it is important to understand the dynamics of violence and its place in modern American culture.

Social Control and Violence

Society has as one of its goals the establishment of social order in which basic human needs are met in a peaceful and regulated process. Social order “does not come naturally and without effort” (Campbell et al., 1969). One of the major challenges of humankind, therefore, is to learn to control violence and other antisocial behaviors which disrupt the peace. In fact, the Kerner Commission’s Report (U.S. National Advisory Commission on Civil Disorder, 1968) indicated that “preserving civil peace is the first responsibility of government. Unless the rule of law prevails, our society will lack not only order but also the environment essential to social and economic progress.”

All societies have dealt with the problem of social order but the challenge is to do so without sacrificing individual liberty and civil rights. Wilson and Herrnstein (1985) indicated that serious crimes, including violent behavior, “are condemned in all societies and in all historical periods by ancient tradition, moral sentiments, and formal law.” In fact, all societies assess the severity of offenses in about the same manner, especially the crimes of murder, theft, robbery and incest. In spite of efforts to maintain complete social order, however, most societies experience fluctuations in control of order from time to time. Since a society may have persons who engage in deviant behaviors, social controls have been developed to handle these individuals and/or groups who have disregard for values of the community or cause disruptions of order in the community.

Violence, then, is a form of *social disorder*. Four political uses of violence were identified by van den Haag (1972). These four uses are: (1) to acquire power; (2) to exercise power; (3) to challenge authority; and (4) to enforce authority. He elaborated on his thesis by presenting examples. Under his first category, to acquire power, he referred to acts of terrorism and revolution. These may not or may be assessed by history as legitimate uses of violence as in the case of the historical legitimization of the American Revolution. The second category, the exercise of power, referred to those circumstances when a person has already “acquired power and uses excessive violence to exercise power” (such as, the dictatorships of Stalin and Hitler). An example of the third category (challenging authority) included riots against a repressive regime and the race riots of the 1960’s in America. Finally, examples of violence to enforce authority included law enforcement activities and war. These are violent behaviors that are accepted and approved by society under certain circumstances. Such circumstances permit violence by governing authority within the parameters of what is considered “legally permissible.”

It is important to remember that “public order in a free society does not and cannot rest solely on applications or threats of force by authorities. It must also

rest on the people's acceptance of the legitimacy of the rule-making institutions of the political and social order and of the rules these institutions make" (Mulvihill and Tumin, 1969). Merton (1957) observed "Power may be legitimized for some without being legitimized for all groups in a society. It may, therefore, be misleading to describe non-conformity with particular social institutions merely as deviant behavior; it may represent the beginning of a new alternative pattern, with its own distinctive claim to moral validity."

The United States has moved from less complex social controls that were deeply embedded in the traditional institutions, such as family and church, to more complex social controls, such as law enforcement agencies. Campbell et al. observed that in contemporary times these social controls are instituted through impersonal, legal, highly formalized and structured governmental organizations, such as law enforcement agencies. In fact, according to Brown (1977), the development of the "modern urban police system" in the mid-19th century was historically significant and was directly related to controlling the urban riots of the times. The second important episode in the history of the modern urban police system occurred in response to the urban riots of the 1960's. Then, the police force became better organized, better equipped and better trained. Thus, the establishment of the professional police force is historically a very recent development.

Historical Factors

A review of the historical literature concerning the social and cultural factors that have molded the American character to tolerate and in fact, perpetuate expressions of violence, has provided some important insights. First, it is clear that our Nation has had a long and intense experience with violence, both state approved and illegitimate, beginning in the colonial era and extending to the present day with violence experienced in all phases of daily living – home, school, church, community, and work.

Second, this history has established a milieu in which violence, legitimate and illegitimate, can thrive and in fact, is openly encouraged in certain circumstances. The legitimate circumstances include state sanctioned violence, such as war. The illegitimate circumstances refer to vigilantism, gang wars, organized crime, and excessive force by the police.

Third, there are certain key elements which increase the potential for violence in America. They include:

- (a) *the media* with its obsession on reporting and describing all types and forms of violence to children and adults in excruciating detail (Miedzian, 1991). Consider the intense and continuous media coverage of Operation Desert Shield, in the early 1990's, which displayed in color and in grisly detail the bombing of Baghdad and the decimation of the Iraqi troops; the war in the Balkans with the vivid description of slaughter, mass graves and rape of women on the side of the opposition; and, more recently, the misogynistic treatment of the women of Afghanistan by the Taliban;
- (b) *the illegal use of drugs and irresponsible use of alcohol* which have been shown to increase the prospect of crime and violence;
- (c) *easy access to firearms*. The accessibility to firearms has been found not only to increase the magnitude of violence but also the lethality of acts of violence. More than thirty years ago when the relationship between access

to firearms and violence was noted, the Kerner Commission's Report recommended the enactment of "laws governing the restriction on the sale of firearms and restricting possibilities of thefts of firearms." Legal and illegal access to firearms still poses problems. Military veterans might choose to keep their weapons as souvenirs rather than leave them with their military units. This practice was noted after the Civil War (Pearson, 1996) but continues to the present time. Rather than accomplish what it intended, the Brady Bill, unfortunately, appears to have been a catalyst for the increase of paramilitary groups, some of whom would raid armories to access weapons (Dees, 1996);

- (d) *the longevity, proliferation, and lethality of gangs* in major cities throughout America. Their influence on many young people has been a serious problem for society. Compounding the problem of gang behavior has been the influence of the drug trade in increasing the growth of gangs; and, finally,
- (e) *the impact of the economy* on the increasing potential for violence, both on an individual and group basis. Accordingly, poverty with its associated problems in accessing basic human needs and the creation of disaffection or anomie has been found to increase the vulnerability of people to act violently and to be victimized. With regard to the effects of poverty on group behavior, the rise of gangs, the urban city riots, and other examples of illegitimate group behavior have been found to be related to violent crimes. Also, the literature revealed that unemployment may increase the potential of some individuals for committing violent crimes. These are persons who have experienced: (1) a conflict between societal values and cultural values, (2) no support systems, (3) poor interpersonal relationships, (4) poor coping mechanisms, (5) poor self-image, (6) poor impulse control, and/or (7) psychiatric problems.

Economic Influences

Research has supported the thesis that economic difficulties and unemployment have had a decided influence on the elevated rates of abnormal behavior (Dooley and Catalano, 1980). When there is a recession, when inflation rates begin to rise and when there is high unemployment, anxiety rises among the population. Unemployment, especially, brings about both financial hardships and personal devaluation. Periods of extensive unemployment are typically accompanied by increases in certain types of maladjustive behavior, such as depression, suicide, and crime (Brenner, 1973). Economic and employment problems affect most seriously those at the bottom of the social ladder who are already vulnerable because of poor education, poor nutrition, broken or unstable families, overcrowding and/or inadequate housing, and feelings of helplessness and rejection by the larger society (Carson et al., 1988).

Unemployment challenges a person's coping ability and management of stress. During the past two decades, we have experienced repeated national episodes of layoffs and firings due to failed businesses; international competition; and corporate greed, scandals and downsizing that have swelled the ranks of the unemployed. The impact of unemployment upon the individual's self-concept, sense of worth, and feeling of belongingness, is shattering. To be continuously unemployed and poor in an affluent society is extremely frustrating and self-devaluating. The vulnerability of the lower socioeconomic segment of the population to these difficult conditions helps explain why there is a

disproportionately higher number of victims who are poor in penal institutions and in mental hospitals as compared with other population classes according to Carson et al.

Wilson and Herrnstein stated that persons who have low incomes and poor employment records are more prone to breaking the law in comparison to persons who are “better off.” Although the explanation for this tendency is related to the income and job status of an individual, there are other factors which must be considered. These include individual characteristics, such as education, racial animosity, parental neglect, age, and peer group experiences.

There are several studies which supported the view that poor urban populations are particularly vulnerable to economic changes within specific communities (Wilson, 1987; Hagedorn, 1988; Sullivan, 1989; Anderson, 1990). These changes included the shift by industry from goods-producing to service-producing with polarization of the labor market into low-wage and high-wage sectors, as well as technological innovations, and relocation of manufacturing industries out of the central cities and in many cases out of the United States entirely (Wilson). The effects are devastating and create social isolation of the inner city population. During the 1980’s, we witnessed the growth of the urban middle class family. With that growth, many middle-class and working-class urban families moved from the inner city with its many problems to more desirable housing and neighborhoods. With their departure, they removed an important “social buffer” that left the inner city residents even more vulnerable to economic change and the development of violent and criminal behavior (Wilson, 1990). The Kerner Commission’s observation that children who grow up in poverty and deprivation in the inner cities would “make them better candidates for crime and civil disorder than for jobs, (that provide) an entry into American society,” appears still to be valid today.

Predispositional Factors of Violence: Family, Individual and Community Influences

The Family

The family is conceived in its broadest sense in terms of type, constellation, and purpose and refers to a group of individuals united by a common affiliation. The type and arrangement of the group of individuals are many and include *but are not limited to* the following constellations:

1. Traditional nuclear family – a family in which a child lives with two married biological parents and with only full siblings if siblings are present. No other people are present in the household.
2. Cohabiting parent-child family – a family in which the child’s parent is living with at least one opposite sex, nonrelated adult. This additional adult may or may not be the biological parent of the child.
3. Parent-child family – a family in which the child is living with a single parent only.
4. Blended families-families that are formed when remarriages occur or when children living in a household share one or no parents. The presence of a step-parent, stepsibling, or half-sibling designates a family as blended.
5. Extended family household is a household where a child lives with at least one parent and someone outside of the nuclear family, either relatives or nonrelatives (U.S. Census Bureau, 2001a).

According to the U.S. Census Bureau (2001b), there were many changes in U.S. family composition. The Bureau reported that in 1996 there were more than 70 million children under 18 years of age living in households. The majority of these children (50.7 million) lived with both parents. Only 3% of these children (1.5 million) lived in unmarried-couple families (parents who were not married to each other).

Among the 18.2 million children living with only one unmarried parent, 16.4 million lived with their mother.

Of the 1.5 million children living in households with adoptive parents, 47% lived with two adoptive parents.

Seventeen percent of all children (11.8 million) lived in blended families. Of these children, 4.9 million lived with at least one stepparent.

There were 15.3 million children living in households with no brothers or sisters present. Among the 56.2 million children living with siblings, 9.5 million lived with at least one step- or half-sibling.

“In addition, there were 10.3 million children who lived in an extended household containing at least one person (of any age) other than a member of their nuclear family (parents and siblings). 4.1 million of these children lived in extended households with grandparents. An additional 1.3 million children were living with their grandparents in households without any parent present, yielding a total of 5.4 million children living with at least one grandparent. When children live in households with grandparents – who themselves are often dependent on the householder (the child’s parent) – family budgets may be strained and children may have to share their parents’ time and resources with their grandparents, especially in situations where their grandparents may require additional care. Children living in grandparent-maintained households were more likely to be in poverty, without health insurance, and receiving public assistance.

Given these constellations, the family as an institution is responsible for a number of significant activities. These include 1. bonding, 2. social learning, 3. moral development, and 4. discipline.

Monahan (1981) stated that the family environment may be critical because of its role in supporting or discouraging violent behavior. He further stated, “The probability of a person being violent may be greater if he or she resides in the family (for example) that encourages robbery as a career and where violence by other family members is a frequent occurrence, than if he or she has support and models for nonviolent modes of interaction and need satisfaction.”

Low family income measured at age 8-10 appeared to be the best predictor of general social failure at age 32 as reported by Farrington and West (1990). Family reliance on government assistance, however, produced another problem. To access a public agency (such as the department of social services) which was responsible for financial assistance, was perceived by society as a charity and by the clients as insensitive and dehumanizing, resulted in lower self-esteem of clients over time, according to Katz et al. (1977).

In a study of violent offenders by Farrington (1991), their experience included poor parental child-rearing methods, poor supervision, and separations from their parents when they were children. Low income, large sized families, poor housing and residence in deprived inner city high crime areas were also found to be associated factors.

Finally, there is a relationship between the child victim of physical abuse and neglect and later violent behavior. These findings were supported by Reiss and Roth (1993) who observed that violent offenders came from certain types of family background and had been subjected to physical punishment, alcoholic or criminal parents and parents who are likely to separate or divorce. Farrington and West reported that the worst offenders tend to come from the poorest families with the worst housing. Physical and sexual abuse of a spouse or child in families was related to the social isolation of that family in the community (Garbarino and Crouter, 1978; Pike, 1990). Some abusers or batterers enforce social isolation on their partners. Being visibly bruised, the victim may have feelings of shame and further withdraw and become isolated from society. Isolation leads to the reduction or absence of systems for family life, integration, or participation in a network of support systems. The family members become isolated from friends, acquaintances, or anyone who may know about the abuse.

The social isolation of families also results in the absence of normal social interactions in their neighborhoods and lack of participation in other organizations (Garbarino and Sherman, 1980).

1. Bonding

The family plays an essential role in the development of a strong, loving interpersonal relationship between the child and the primary caregiver. When this relationship is disrupted, it may result in behavior which, together with other factors, later leads to acts of violence as reported by Farrington (1989). For example, separations from parents early in the life of the child may contribute to the development of adult violence. Wilson and Herrnstein observed: "an affectional bond that an infant forms between himself and his mother figure tends to be enduring and independent of specific situations. It develops in clear stages, beginning with undifferentiated responsiveness of the newborn infant to any figure, through specific attachment to an identifiable person and onto a development in the child of a sympathetic understanding of the parents' point of view."

Attempts have been made to explain the circumstances when bonding may or may not have a decided negative impact on the personality development of the child. Rutter (1972) stated that "an affectional bond which is disrupted by parental discord or separation" may result in temporary problems "but may not have long term consequences. If the bond never forms, consequences can be very severe and may lead to affectionless psychopathy," which is described as beginning with "an initial phase of clinging, dependent behavior, followed by attention-seeking, uninhibited, indiscriminate friendliness, and finally a personality characterized by the lack of guilt, an inability to keep rules, and an inability to form lasting relationships." Agreeing with this observation, Ainsworth (1973) contended that the most important long term results of the failure to form an affectional bond are the "inability to establish and to maintain deep and significant interpersonal relations." Reiss and Roth wrote about "identification" rather than "bonding" but make no distinctions. Bonding has been used to identify the establishment of intense and emotional relationships between parent and child which occurs at birth. Identification (or cognitive development) according to Reiss and Roth refers to the sharing of common beliefs, perceptions about social class and ethnicity and common psychological behaviors. They reported that by the age of 5-6, children begin to identify

with their family and everything it represents. Therefore, if the parents possess undesirable behaviors, the child may adopt these behaviors. For example, if the parents are aggressive, punishing, and harsh, the child may develop these same behaviors in later life. Some family violence may be caused by recent changes in family organization and structure which may affect the social and moral bonding among family members. This may include persons with disabilities. Another change is related to the temporary placement of children in foster homes, in adoptive homes, and with relatives. These placements may expose some of the children to the risk of violence from caregivers where bonding has not been established and where the caregivers are less responsible for the care of the child. Because of serial cohabitation, divorce, and desertion, another major change is the increase in the number of children who are not living with their parents.

Lacking the bonds of parenthood may result in the risk of violence to minors in the family, especially female adolescents who become targets for sexual violence (Reiss and Roth).

Foster care has been studied to determine its importance in the mental health of the child. It has become clear that the more changes in placement a child experiences, the greater the likelihood of adult criminality and violent criminal behavior (Hensey, et al., 1983; Lynch and Roberts, 1982; and Widom, 1990). Specifically, frequent placements can impact adversely on a child's emotional development and, with other factors, lead to adult violent behavior. As of September 30, 1999, there were 568,000 children in foster care. The median age of children was 10.1 years. 52% were male and 48% were female (U. S. Department of Health and Human Services, 2001).

2. Social learning

It is within the context of the family that learning first takes place. Eron (1990) has indicated that aggressive or violent behaviors are learned responses to frustration and may become instruments for achieving goals. The parental models, especially, facilitate the aggressive or violent behavior. Bandura and Walters (1963) reported that "physical abuse, parental modeling of aggression, and permissiveness toward aggressive behavior encourage aggression in boys." Other researchers found a high incidence of psychopathic traits in the parents of delinquents. The traits included "alcoholism, brutality, antisocial attitudes, failure to provide, frequent unnecessary absences from home, and other characteristics that made the parent an inadequate and unacceptable model" (Bandura, 1973; Glueck and Glueck, 1969; and Ulmar, 1971).

Social learning may have a decided effect on the general development of the child. Children who are victims of violence suffer delays in physical, social and emotional development. Even children who witness violence (third party involvement) may suffer from posttraumatic stress disorders or as it has recently been called, in some situations, "urban stress disorder." The impact is compounded when children must participate as an official witness in court (Eth and Pynoos, 1984).

3. Moral development

According to Kohlberg (1978), the development of moral reasoning progresses through three levels, with two stages at each level. At the lower stages of moral reasoning are concreteness and egocentricity. At the higher

stages are abstract concepts of justice and rights and are more social in orientation. It is postulated that delinquent behavior is related to the delay in the development of moral reasoning. In examining this speculation, Nelson et al. (1990) indicated that the strength of the relationship between moral reasoning and delinquent behavior must take into account a number of other variables, such as cognitive development and within group differences.

Wilson and Herrnstein proposed that persons who engage in criminal behavior are deficient in three factors arising from family experiences: development of attachment or bonding, the development of understanding of consequences over time, and the development of conscience. Carson et al. observed that antisocial personalities are unable to understand and accept ethical values except on a verbal level. Their conscience development is severely delayed or nonexistent and they act out their problems without any apparent guilt or anxiety. Lykken (1957) and Eysenck (1960) stated that the psychopathic individual fails to acquire many of the conditioned reactions essential to normal avoidance behavior, conscience development, and socialization.

4. Discipline

Caretakers in families use discipline in response to certain undesirable behaviors in children. It has been the subject of research and study as one of the factors with the potential to increase a child's propensity toward violence.

It has been found that inconsistent or noncontingent discipline results in aggression in children. In a landmark study, Patterson (1982) concluded that parents of problem children did not make their use of penalties contingent on the child's behavior. Specifically, they did not state clear rules, monitor compliance with the rules, or punish violations of the rules. The author further stated, "The irritable parent who does not use discipline effectively, tends to produce aggressive children."

It has been observed that common sense permissiveness usually leads to a child who is social and creative. If, on the other hand, the caregiver is overly permissive and there is a lack of discipline, this tends to produce a spoiled, aggressive, inconsiderate and insecure child (Carson, et al.). A number of studies (Faretra, 1981; Patterson, 1979) indicated severe discipline which uses physical punishment for broken rules, increases aggressive behavior in children. It also may provide a model of aggressive behavior that children may imitate.

When parental rejection is coupled with severe punishment, the child has slow conscience development and exhibits aggression.

The Impact of Family Violence on the Development of the Child

The violent crime of spousal abuse

Feminist theory recognizes the unequal distribution of power between men and women in most societies. According to this theory, therefore, women are subject to male dominance which keeps them in subordinate positions in the family, at work, and in the community. Finkelhor (1983) stated that men use their physical and social powers to subjugate women and to maintain their dominant position. The power struggle extends to the sexual relationship as well as to work and social relationships.

Stark and Flitcraft (1991) defined spousal abuse or interspousal violence as “the use of physical force in intimate relationships among adults.” They continued, “Battering is defined as a syndrome of control and increasing entrapment attendant upon spouse abuse and characterized by a history of injury, general medical complaints, isolation, stress-related psychosocial problems and unsuccessful help-seeking. Among the most commonly reported psychosocial problems linked to battering are rape, substance abuse, attempted suicide, depression, and child abuse. Either partner or both may be abused. However, the syndrome of entrapment associated with battering has been identified as a problem only among women.”

The Attorney General’s Family Task Force (1998) reported the following statistics about domestic violence:

a. Domestic violence in general:

1. It is estimated that one out of six women are victims of domestic violence.
2. Domestic violence occurs between 50% to 60% of all married couples
3. Injuries inflicted in domestic violence incidents are as serious or more serious than injuries inflicted in 90% of all violent felonies.
4. Estimates of the proportion of domestic violence incidents not reported to police vary from 48% to 99.6%.
5. Nine out of ten murdered women are murdered by men. Four out of five are murdered at home. Three out of four are murdered by husbands or lovers. Almost none are killed by strangers.
6. One out of four suicides among women is precipitated by domestic violence.
7. Estimates that child abuse is present in battering relationships range from 13% to 75%.

b. Domestic violence nationally:

1. It is estimated that 2,000 to 4,000 women are beaten to death annually.
2. Nearly six million women will be abused by their husbands in any one year.
3. Domestic violence is the single major cause of injury to women in this country, more significant than auto accidents, rapes or muggings.

c. Pregnant battered women:

1. Men who batter pregnant women are 3 times more violent outside the home.
2. 25% to 45% of battered women are battered during pregnancy.
3. Battering may lead to miscarriage.
4. Pregnant women in battering relationships have increased risk of low birth weight infants.

d. Domestic violence is one of the most common of all crimes:

1. Acts of domestic violence occur every 15 seconds in the U.S.
2. About one-half of all couples experience at least one violent incident: in one-quarter of these couples, violence is a common occurrence.
3. In almost three quarters of reported spouse assaults, the victim was divorced or separated at the time of the incident.

e. Most family violence is committed against women:

1. 95% of all spousal assaults are committed by men.
2. 21% of all women who use hospital emergency surgical services are battered.

f. Relationship between battering of women and child abuse:

1. One third of the children who witness the battering of their mother demonstrate significant behavioral and/or emotional problems, including psychosomatic disorders, stuttering, anxiety and fears, sleep disruption, excessive crying and school problems.
2. 90% of abused boys and 75% of boys who witness battering have total behavioral problems above standardized norms.
3. At least 1/3 of all men who beat their wives also beat their children.

g. Male sexual assault:

1. It is estimated that 7-10% of all adult rape victims are male.
2. Rape is the most under-reported violent crime with only 5-20% of all victims reporting. Even fewer male victims report.

h. Prosecution of rapists:

According to conservative estimates, as many as 84% of rapes each year are never reported.

The violent crimes of child abuse and neglect

Sedlak and Broadhurst (1996) stated, "...female children are three times as likely as males to be sexually abused. Boys had a greater risk of emotional neglect than girls. Children are consistently vulnerable to sexual abuse from age three on." However, among males, there was a greater prevalence of serious injuries.

In commenting about socioeconomic status (measured by family income) and child abuse and neglect, research has indicated that there is a substantial relationship between the two factors. "For children from families with incomes less than \$15,000, the rate of physical abuse was three and one-half times greater and the rate of sexual abuse was six times greater than for other children. The general pattern that physical abuse was more frequent than sexual abuse held for both high-income and low-income families. The seriousness of injury or impairment was substantially related to family income: the rate of: (a) serious injury was almost seven times greater, (b) moderate harm nearly five times greater, and (c) probable injury seven times greater for children from lower-income than from higher-income families.

Victims of child sexual abuse display fear, immaturity, and neurotic behavior as well as high levels of aggression and antisocial behavior. Although one fourth of all sexually abused children are males, thirty eight percent of children who were sexually abused in day care centers were male" (Finkelhor, 1991; Finkelhor et al., 1988; Finkelhor & Associates, 1986).

Newberger (1991) reported that abused boys were more likely than others to have been exposed to high demands for adult behavior. Also, almost half of the abused boys (a) died when they were unusually young; (b) were in later life convicted for serious crimes, (c) became alcoholic, or (d) became mentally ill. They had higher rates of juvenile delinquency when compared to boys with loving parents who were not abusive. It was also found that parental alcoholism and criminal behavior

are associated with higher frequencies of later antisocial behavior in children. Boys who were sexually abused developed a greater propensity for violent behavior. The psychological action of turning from victim to victimizer may provide the offender with the feeling that he is no longer vulnerable and has proved mastery over his sense of helplessness. Groth and Birnbaum (1979) indicated that child sexual abuse was found in the histories and psychological characteristics of incarcerated pedophiles, rapists and murderers.

Widom (1989) reported that neglect in childhood without violence was just as likely as physical abuse to lead to an arrest for violence in adult life.

In addition, the Attorney General's Family Task Force (1998) reported the following statistics about child sexual assault:

1. The average victim of child sexual abuse is between 8-11 years old.
2. One of four girls and one of six boys under the age of 18 are child sexual abuse victims.
3. One of five victims is under 12. 10% of all rape victims are under age 5.
4. Incest is the most common form of sexual abuse.
5. In presently reported cases, 90-97% of abusers are men.
6. Child sexual abuse is rarely a one-time occurrence. Abusive relationships last an average of 1-4 years; many last much longer.

The Individual

In examining characteristics within the individual which may lead to increased propensity toward violent behavior, six major factors were identified: genetic factors, prenatal and postnatal nongenetic factors, gender, intelligence, personality, and age.

Genetic factors

The studies on the relationship between genetics and subsequent criminal behavior supported the proposition that there is an inherited factor which, in part, explains why criminal behavior may be found in families (Mednick et al., 1984). The genetic predisposition may or may not be activated according to other factors, such as family and home environment, the community, and the influence of peers (Mednick et al., 1984).

Prenatal and postnatal nongenetic factors

There is limited evidence that prenatal and birth complications may cause subtle neurological problems which result in subsequent antisocial behaviors in later life. The effects of toxins and other teratogens on the embryo and fetus during pregnancy have been cited as possible causative factors which should be prevented. (Mednick & Kandel, 1988). Reiss and Roth indicated that traumatic head injuries in children and adults may account for hyperactive and/or impulsive behaviors often associated with violent activity.

Gender

The male/female ratio in criminality was examined to determine the reasons for the substantial difference in the rate of violent crime. The issue of gender as a factor in understanding the process which spawns the development of potential perpetrators is significant. Many studies have shown that there is a male-female gap in the commission of violent crimes (Cowie et al., 1968; West & Farrington, 1977). In further support of this differential, the FBI's Uniform Crime Report

(Federal Bureau of Investigation, 2002) provided recent data on violent crime according to the factor of sex and age. The FBI identified four offenses which fall under the category of “violent crimes.” These are murder and nonnegligent manslaughter, forcible rape, robbery, and aggravated assault. For the purpose of this Report, two categories were examined: (1) murder and nonnegligent manslaughter and (2) aggravated assault. Murder and nonnegligent manslaughter were defined as the “willful killing of one human being by another.” Of the 9,426 murders committed in 2001, 8,252 (87.5%) males were arrested as perpetrators; 1,174 (12.4%) females were arrested. Of the known offenders of murder, therefore, a ratio of male to female was approximately 7:1.

Another category of violent crime, reported by the Federal Bureau of Investigation, was aggravated assault. This was defined as “an unlawful attack by one person upon another for the purpose of inflicting severe or aggravated bodily injury. This type of assault is usually accompanied by the use of a weapon or by means likely to produce death or great bodily harm.” In 2001, of 329,722 persons arrested for aggravated assault, 80% (263,559) were male and 20% (66,163) were female with a male/female ratio of 4:1. In seeking reasons for this gender gap, many researchers have cautioned against making dangerous generalizations.

But in view of these data, males are obviously the predominant perpetrators of homicide and aggravated assaults. As an explanation of the predominance of males, Mednick et al. (1982) reported that high levels of testosterone in the blood may directly affect violent behavior of males or the influence of the sex hormones on fetal brain development may influence violent behavior in males at a later time. Others have proposed that early adolescence is the time when males and females sharply differ in antisocial behaviors. This may be due to the socialization process in sex role differentiation when “primary and secondary reinforcers of adulthood emerge” and become ingrained (Wilson & Herrnstein).

Some studies have focused on the reasons for substantially fewer female offenders of violent crimes. Beginning with the landmark study of female offenders by Glueck & Glueck (1930), factors that were assessed to predispose females to crime were almost the same as those for males. These include poor family background, poor childhood behavior, low intelligence, and emotional instability. The Gluecks stated, “The women are themselves on the whole a sorry lot.” Other researchers added the factors of loneliness, hostility toward school and family, low self-image, an incapacity for friendship, and a turbulent onset of puberty (Cowie et al., 1968; Konopka, 1966; Vedder & Sommerville, 1970). As an explanation for the gender gap, therefore, it is posed that female offenders are even more deviant in these predisposing factors than males because females require a greater degree of deviancy before they are pushed into violent crime.

Some researchers attribute the high rate of male offenders in the execution of such crimes to the male hormone and development of the role model in adolescence. Female offenders, on the other hand, are fewer in number and those who are offenders are noticeably deviant in their social behaviors.

Intelligence

The factor of intelligence in criminal behavior has been the focus of many studies over decades of research. In the judgment of this author, the role of intelligence in criminality is not well understood. Intelligence should be examined in relationship to the multifactorial influences of the environment in which a child develops. Until such studies are undertaken and replicated, the impact of intelligence on the development of criminality is speculative at best.

Personality

The personality of criminals has been a constant source of examination throughout the history of psychology. It appears that many criminals who engage in acts of violence are identified by the following characteristics: inadequate conscience development with no sense of guilt, impulsive and irresponsible behavior, exploitation of others and avoidance of blame for their deviant behavior, rejection of authority, lack of learning from experience, and inability to establish and maintain good interpersonal relationships. Among those with antisocial personalities who commit the violent crimes of homicide and aggravated assault are persons who are prone to acting out impulses in remorseless and often senseless violence. Agent A.C. Brantley of the Federal Bureau of Investigation (personal communication, November 13, 1993) provided a list of traits and characteristics of violent offenders:

Traits:

1. "Low frustration tolerance – reacts to stress in self-defeating ways, unable to effectively cope with anxiety, acts out when frustrated. Frustration leads to aggression.
2. Impulsive – is quick to act, wants immediate gratification, has little or no consideration for the consequences, lacks insight, has poor judgment, has limited or impaired cognitive filtering.
3. Emotional lability and depression – quick tempered, short-fused, hot-headed, "flick," rapid mood swings, moody, sullen, irritable, humorless.
4. Overly sensitive – hypersensitive to criticism and real or perceived slights, suspicious, fearful, distrustful, paranoid.
5. Preoccupation with violent themes – movies, books, TV, newspaper articles, magazines (detective), music, weapons collections, guns, knives, implements of torture, S & M, Nazi paraphernalia.

Characteristics:

1. Victim of childhood abuse – sexual and physical abuse, maternal or paternal deprivation, rejection, abandonment, exposure to violent role models in the home.
2. Loner – is isolated and withdrawn, has poor interpersonal relations, has no empathy for others, and lacks feelings of guilt and remorse.
3. Altered consciousness – sees red, blanking, blackouts, derealization/depersonalization ('it's like I wasn't there; it was me but not me'), impaired reality testing, hallucinations.
4. Threatens violence – toward self and/or others, direct, veiled, implied, and conditional.

5. Blames others – projects blame onto others, fatalistic, external locus of control, avoids personal responsibility for behavior, views self as ‘victim’ vs. ‘victimizer,’ self-centered, sense of entitlement.
6. Chemical abuser – especially alcohol, opiates, amphetamines, crack and hallucinogenic drugs (PCP, LSD), an angry drunk, dramatic personality/mood changes when under the influence.
7. Mental health problems requiring in-patient hospitalization – especially with arrest history for any offenses prior to hospitalization.
- 8.*History of violence – towards self and others, actual physical force used to injure, harm, or damage.
9. Odd/bizarre beliefs – superstitious, magical thinking, religiosity, sexuality, violent fantasies (especially when violence is eroticized), delusions.
10. Physical problems – conditions which may contribute to poor self-image, lack of self-esteem, and isolation.
11. Pathological problems at home, school and community – fire setting, enuresis, cruelty to animals, fighting, truancy, temper tantrums, inability to get along with others, rejection of authority.”

* THIS ELEMENT (HISTORY OF VIOLENCE) IS THE MOST SIGNIFICANT IN ASSESSING INDIVIDUALS FOR POTENTIAL VIOLENCE.

Therefore, certain personality traits are identified as significant precursors of violence. These traits are well established in childhood and persist throughout life. Among the most important precursors are *history of violence, threats of violence, and emotional instability or depression.*

Although the majority of violent crimes are committed by persons with antisocial personalities, there are some crimes that are committed by persons who do not have deviant personalities (Carson et al.).

Age

Finally, as an individual factor, age has been studied to determine its relationship with the perpetration of violent crime. From the evidence, violent crimes appear to be predictable because the precursors are found in childhood and adolescence and extend into adulthood. Also, for a variety of reasons, murder and aggravated assault are committed by young and middle age adults. For example, the Federal Bureau of Investigation reported that “nationally, adults make up 83.3% of the persons arrested in the U.S. during 2001. Approximately 45.9 % of the total arrests nationwide involved persons under the age of 25; 31.4 % were under the age of 21; and 16.7 % of the total were under the age of 18. In terms of violent crime arrests, 44.2% of total arrestees were under 25; 29% were under 21; and 15.4% were under 18.”

Studies show that the most violent people at one age tend also to be the most violent at another. According Farrington (1989, 1991), the potential for aggressive behavior is persistent from infancy to adulthood. Children who exhibit aggressive behavior at around age 8 are more likely than others to exhibit delinquent, criminal, or violent behavior in adolescence and adulthood. Aggressive behavior continues regardless of environmental influences which occur during the late teenage years, or as children leave school, their parent(s) homes, and sometimes their communities.

Reiss and Roth indicated that there are many risk factors that emerge during the preschool and early school years. The most common risk factors include fearlessness, attention deficit, inability to defer gratification, and restlessness. These and especially early school failure are the most significant predictors of childhood aggressive behavior. These observations are confirmed by a number of longitudinal studies which found that children who display serious antisocial behaviors early in life are at a much greater risk to become violent adults. The adults are at further risk for a broad spectrum of psychological problems, including alcoholism, criminality, and poor adjustment to school, marriage, and work.

The factor of age is important; for example, an analysis of the FBI data for 2001 indicated that rates for aggravated assault in the U.S. peaked at age 25-29 and then decline very gradually thereafter. Wolfgang (1958) posited that overt violence diminished with maturity because of the biological changes of aging. The rapid decline in reported assault cases among the older population, however, may be an underestimation of the proportion of older individuals who perpetrate violence in the United States. It is speculated that older persons probably choose victims, such as family members or subordinates, who are reluctant to report violence to authorities. Age, therefore, is significant in determining peaks of occurrences when violent crime is committed during the lifespan of offenders.

The Community

Reiss and Roth (1993) discussed the community and its impact on the creation of violence. Here, community refers to a group of people with common interests, living and/or interacting together in a common location. When one analyzes the various characteristics of the community, its contribution to violence becomes obvious. Common characteristics of the communities with high rates of violence included *high population density, teenagers in the population, single parent households, and poverty*.

1. A community with high population density alone may not necessarily be a determinant of violence, but combined with other elements appears to be the appropriate setting.
2. With regard to the high rate of teenagers in communities with high rates of violence, Newman (1979) has found that “this period (of adolescence) is often accompanied by rebelliousness, intense increase in sex drive, moodiness and general aggressivity.” These are contributing factors which lead to the high rate of violence in the teenage population.
3. Single parent households are only significant if child care and supervision are not adequate. Studies of urban families in poverty have shown that there is a higher rate of abuse and neglect of children from single parent households, especially if there is no extended family support system. As cited earlier, the U.S. Census Bureau reported that in 1996, 16.4 million children lived with only their single mother and 1.8 million lived with only their single father.
4. Finally, poverty is one dimension of the community, referring primarily to socio-economic descriptors. The concept of poverty is related to a number of factors, including low economic income (usually below what is considered adequate for maintenance of good health and quality of life), substandard housing, and lack of adequate social support systems. Poverty is measured by these criteria and is found in both urban and rural geographic areas.

As a factor which contributes to the development and expression of violence, poverty has been extensively studied. First, it is identified as a factor associated with a high number of urban murders, especially of close friends and acquaintances, children and spouses, and with robbery-associated murders of strangers (Curtis, 1975; Rose, 1979; Wolfgang and Ferracuti, 1967; and Reiss and Roth). A closer look at this phenomenon by Smith and Parker (1980) revealed that poverty is strongly associated with murders of family members and close friends rather than murders of strangers.

The multi-dimensional variable of poverty has been implicated time and again as a major factor in breeding violence. *It appears, therefore, that the elimination of poverty alone will substantially reduce violence.* Since the causes of violence are multifactorial, they, in total, explain the creation of this behavior. Therefore, the effects of poverty should be placed in their proper perspective:

1. Poverty is a major contributor to the development of violence.
2. Poverty, combined with other major determinants such as belief in male dominance and racial discrimination, will increase expressions of violence.
3. Poverty has been the breeding ground for gang behavior, particularly in urban areas.

The U.S. Census Bureau (2002) reported:

“The poverty rate in the year 2001 was 11.7 percent, up from 11.3 percent in 2000. People below the poverty thresholds number 32.9 million – 1.3 million higher than the poor in 2000.

At 16.3%, the poverty rate for children remained higher than that of any other age group: 11.7 million children were poor. They represented a disproportionate share of the poor population (35.7%) as they were only one-fourth (25.6%) of the total population. Children under 6 have been particularly vulnerable to poverty. In 2001, the poverty rate for related children less than 6 years of age was 18.2%. Of children under 6 living in families with a female householder, no spouse present, 48.9% were poor, over five times the rate of their counterparts in married-couple families (9.2%).

The number of single mothers increased between 1970 and 2000, from 3 million to 10 million. Over the same time frame, the number of single fathers increased from 393,000 to 2 million. (Single parents include all those who are not currently living with a spouse.)

In 2001, there were 6.8 million poor families up from 6.4 million in 2000.

The drug economy

An industry for sale of drugs arose in the inner city because of the increased demand by users; the desire for easy money, which some believed, would lift them out of poverty; and the element of “glamour” in the industry. Anderson (1990) indicated that for many young men in the inner-city, the drug economy was an employment agency “superimposed on the existing gang network.” These young men who were without clear job opportunities to rise out of the inner city became readily involved in the distribution and sale of drugs. The money from the drug activity was used to support themselves and their families. But associated with the drug economy was violence. For example, rival drug dealers claimed their own

territoriality with lethal results and high rates of murder. In addition, in order to “feed their habit,” the users of drugs engaged in desperate acts which could become violent. The effects of certain drugs may result in aggressive behavior that could lead to violence. Furthermore, because the drug economy is an illegal activity, law enforcement may intercede and, in doing so, violence may erupt.

It is apparent that the social isolation and neglect, feelings of disenfranchisement, as well as the stigma of poverty resulted in the rise of the drug economy in the inner city. Though the distribution and sale of drugs may have been created by these predisposing factors, the use and sale of drugs now have evolved as a major factor that, in and of itself, creates violence.

In summary, the roles of the family, the individual, and the community in the creation of violence have been reviewed. The findings which have the greatest importance for understanding the predispositional causes of violence are:

1. There is a relationship between the victim of physical abuse and neglect as a child and his later violent behavior.
2. The worst violent offenders come from the poorest families with the worst housing.
3. The family is the context in which bonding takes place. If adequate bonding does not occur, it is speculated that the child will become at risk for antisocial behavior and his/her future interpersonal relationships will be faulty.
4. The more changes in placement a child in foster care experiences, the greater is the likelihood of adult criminality and violent criminal behavior.
5. Children who witness violence may suffer from posttraumatic stress disorders.
6. Severe discipline which uses physical punishment increases aggressive behavior in children and may provide a model of aggressive behavior that children imitate.
7. Parental alcoholism and criminal behavior are associated with higher frequencies of later antisocial behavior in children.
8. There is a higher rate of abuse and neglect of children from single parent households, especially if there is no extended family support system.
9. The multi-dimensional variable of poverty has been identified time and again as a major factor in breeding violence. Further, when combined with other determinants, such as the belief in male dominance and racial discrimination, poverty has been a breeding ground for gang behavior and will increase expressions of violence.
10. The distribution and sale of drugs arose in the inner city because of increased demand by users, the need for income which would lift the inner city resident out of poverty and the glamour and excitement associated with the illegal trade. The drug economy brought violence by those who became territorial in their distribution and trade and by those who were users of certain drugs. Law enforcement efforts to intervene also led to violent confrontations.
11. In individuals, genetic factors, perinatal and postnatal nongenetic factors, gender, intelligence, personality and age may lead to an increased propensity toward violence.

Precipitating Factors of Violence

Reiss and Roth indicated that most precipitating factors of violence or “triggering events” occur before the act when people attempt to communicate with each other. Such communicative acts include “disputes, threats and counter threats, exchanges of insults, robbery and resistance, and the urgings of bystanders.” Furthermore, these exchanges were affected by “preexisting social relationships among participants: an intimate relationship, a power or status hierarchy (e.g. guard/inmate, weaker/stronger, armed/unarmed, shielded/vulnerable) or a culturally defined relationship (e.g. membership in rival gangs; or in different ethnic groups, or in a ‘hate group’ and the category against which it is prejudiced). The risk of violence in a verbal exchange may be increased by communication impairments, for example, that are due to language barriers, to culturally defined connotations of words, and to different definitions of insults, or to the influence of alcohol or other drugs.”

Reiss and Roth continued with their observation that these events that trigger violence are affected by the mental and physical state of the perpetrator at that time. “Accumulation of *flash* emotions – anger, frustration, stress, fear, for example, all contribute. Premeditation, sexual arousal, or urges to *prove one’s manhood* sometimes play roles.”

Furthermore, the setting in which interactions occur may influence the perpetration of violence. Location, physical characteristics of the environment, and access to a security system may increase or decrease the probability of perpetrating violence.

Monahan (1986) postulated that violence develops out of a cycle of stimuli and responses. Initially, there is a *stressful* event that has occurred. The stressful event may be any event that the individual perceives as a demand or threat to his/her well being, such as insults, assaults, job changes including termination or discipline, and other life events.

Next, the person reacts to the event by *appraising* the situation to determine its importance or intentionality and by having *expectations*, that is, thinking of what will happen because of the event or how his/her behavior could change the outcome. The process of appraising and having expectations about the outcome is reflective of the beliefs of the individual and his or her perception of the world. Individuals are predisposed toward or away from violent reactions by this cognitive process.

Then, the *emotional* reaction occurs. During times of stress, emotional reactions that might cause violence include terror, hatred, and/or anger. However, guilt or empathy might have an inhibiting effect.

The final phase in the violence cycle is *action*. This response will either be fight or flight, that is to commit violent behavior or to avoid it. These cycles may occur repeatedly.

In summary, violence is generally triggered by communicative acts that may be the result of a threat or insult to an individual. Rosenberg and Fenley (1991) indicated “The most frequently occurring circumstance associated with homicide is verbal argument.”

It is hoped that this overview will be helpful to put in context the concept of crimes of violence and the comments and recommendations contained in the next chapters.

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CHAPTER THREE:

WHAT IS THE SCOPE AND MAGNITUDE OF THE PROBLEM?

Based on a review of the literature, deliberations of the Conferees, and the information from the Commissioned Papers, there are some data that contribute to an understanding about the scope and magnitude of the problem. There are gaps in information, however, and there is a critical need to mount a national effort that builds a reliable and valid database on violence and disability. Information is especially needed to answer the question about the number and the characteristics of individuals with disabilities who become victimized and receive treatment and follow-up care. S. Madison (CR*, 2002) recommended that all Federal surveys on violence include disability in their protocols and datasets.

In an effort to present what is currently known about the scope and magnitude of the problem, we begin with the key citations that provide valuable information. The reported findings are based on limited studies that need to be interpreted with caution since some of the data are suggestive and indicate general trends. The need to create and implement a reliable and valid national survey on violence and disability becomes a repeated theme throughout the literature and during the deliberations of the National Conference. J. Whatley (CR) and M. Dubin (CR) concurred with the maxim that “accurate statistics are needed because data drive funding.” As part of the endeavor to obtain accurate information about the scope and magnitude of the problem of violence and disability, it is a professional mandate that while we survey needs and characteristics, we continue to provide the best possible services for those in need (E. Briggs, CR).

The statistical reports that follow are grouped into two categories: (1) children with disabilities and (2) adults with the disabilities. In some instances, the findings are relevant for both children and adults. As stated in Chapter One, the term violence is used as the rubric for criminal behaviors and outcomes that are perpetrated by an individual against another individual, resulting in harmful and destructive consequences. For further information about the definition of violence see Chapter One.

Current Statistical Findings about Children with Disabilities

After a comprehensive review of the literature on the topic of children with disabilities who become victims of violence, Sullivan (2002) stated, “The lack of data on the victimization of children and youth with disabilities is universal across the major criminal justice and child maltreatment databases mandated, compiled, and maintained by the federal government.” She continued by indicating that this lack of information has been the major barrier for understanding the scope and characteristics of violence and disability. Further, information about conventional violent crimes (e.g. homicides, assaults, theft, and robbery) against children with disabilities is even more limited because crime victimization surveys do not recognize or identify this population.

In recognition of the dearth of information about crime victimization of children and adults with disabilities, Congress passed The Crime Victims with Disabilities

**CR means conference remarks by participants at the Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities, May 6 - 7, 2002.*

Awareness Act (1998). The bill proposes to include disability status in the U.S. National Crime Victims Survey (NCVC) (Personal Communication, Michael Rand, U.S. Department of Justice, 2001). C. Hoog (CR) indicated that the NCVC will be strengthened and more valuable if it is modified to include all types of disabilities in addition to developmental disabilities.

Relevant studies that provide estimates

1. Among a sample of 482 consecutively referred disabled and maltreated children in a hospital, the most common forms of violence were sexual abuse or a combination of sexual abuse and physical abuse (Sullivan et al., 1991).
2. In a five-year retrospective study of 4,340 children with disabilities in a pediatric hospital, it was reported that 68% were victims of sexual abuse and 32% were victims of physical abuse (Willging et al., 1992).
3. A hospital based epidemiological study reviewed 39,000 hospital records that covered a ten year period of time (1982 - 1992). Out of the total number of records examined, approximately 6,000 were found to have been victims of violence or a prevalence rate of 15%. Of the 6,000 victims, 64% were children with disabilities (males 56%; females 44%) who were categorized as follows: behavior disorders (37.5%), speech-language disorders (8.7%), mental retardation (6.2%), hearing impairments (6.1%), learning disabilities (5.7%), and other disorders (4.1%). Types of violence perpetrated against these children included neglect, physical abuse, and sexual abuse. Over half the sample (54%) had been exposed to multiple forms of violence (Sullivan & Knutson, 1998).
4. In a school-based epidemiological study, 39,800 school records from the Omaha public schools during the 1994-95 school year were examined for violence and disability. Of the total, 11% or 4,378 children in the public schools were judged to be victims by violence. Of those public school children victimized, 22% or 963 had disabilities. The disabilities were categorized as follows: 37.4% behavior disorders, 24.1% mental retardation, 16.4% learning disabilities, 11.2% health related disabilities, 6.5% speech-language disorders, 1.3% hearing impairment, 1.2% multiple disabilities, 1.2% orthopedic disabilities, 0.4% visual impairment, and 0.1% autism (Sullivan & Knutson, 2000).
5. There is some evidence about disabilities that are *caused* by violence but limited epidemiological data are available. Since 1973 information has been collected on persons who have acquired spinal cord injuries (SCI) by the Model Spinal Cord Injury Care System Program sponsored by the National Institute on Disability and Rehabilitation Research. Almost 17% of all spinal cord injuries that occurred have been caused by acts of violence (DeVivo, 1995). And, almost all of these injuries were caused by gunshot wounds with the exception of occasional instances of stabbings, other assaults, and explosions. The data should be interpreted with some caution because they do not distinguish between intentional and unintentional acts of violence; therefore, all causes were considered acts of violence whether or not they were intentionally inflicted. One of the most alarming trends in the data base is as follows: the percentage of spinal cord injuries caused by acts of violence has increased steadily from 13.3% in the mid-seventies to 30.4% since 1991. In 1995, DeVivo reported that acts of violence have moved from the fourth to the second leading cause of spinal cord injury and are now within 5% of the leading cause which is motor vehicle crashes.

A more recent report from the Model Spinal Cord Injury Care Systems (National Institute on Disability and Rehabilitation Research, May 2001) indicate that, since 1990, motor vehicle crashes account for 38.5% of the SCI cases. Next in the causes of SCI are acts of violence, primarily gunshot wounds, accounting for 24.5%, followed by falls at 21.8%. Sports injuries resulted in 7.2% of the SCIs. The slight discrepancy between the DeVivo report and the more recent report by the National SCI Statistical Center at University of Alabama at Birmingham is related to differences in definitions and data collection methods. Both sources note a trend that shows a gradual increase in the etiology by acts of violence and decrease in other causes.

6. In a study of Violence as a Cause of Traumatic Brain Injury (Harrison-Felix et al., 1997), it was reported that of the 50,000 deaths related to traumatic brain injury (TBI) in 1992, approximately 44% were caused by firearms compared to 34% caused by motor vehicle crashes. In 1991, violence was the cause of 9% of 1.5 million cases sustaining a non-fatal TBI.

To study differences in cases with TBI caused by violence and non-violence, Harrison-Felix (1998) studied 803 cases with 29% or 234 resulting from violence and 71% or 569 from non-violence. The majority of the TBI's resulting from violence or approximately 56% were caused by blunt assaults which included blunt objects, unarmed fights or jumps. Twenty three percent were caused by penetrating objects, including firearm injuries (19%) and unknown (4%). The study concludes, "At time of injury, individuals with violence-related TBI tend to be in the older age groupings, male, non-white, unmarried, living alone, less educated, and not employed."

7. A population based study of pediatric firearm injuries over a one year period identified 11.7% mortality rate and a 10% permanent disability rate (Dowd et al., 1994). The injuries resulted in physical disabilities. Unfortunately, there were no data on the premorbid disability status of the children who ranged in age from birth to 16 years.
8. Goldson (1998) reported on a one year study of all confirmed cases of violence against children who were diagnosed at a children's hospital in 1994. Of a total of 812 cases, 21% or 170 were disabled. In addition, 56% or 455 had behavior problems.
9. In another citation, Goldson reported that the prevalence of violence against children with disabilities in 1991 was 35.5 of 1,000 children with disabilities as compared to a prevalence of 21.3 per 1,000 children without disabilities.
10. Sobsey and Doe (1991) reanalyzed data from 1973 to 1984 from Baltimore, MD, concerning 500 children who were victims of violence. They found that children with disabilities were victimized 4.43 times greater than those children without disabilities.
11. There is a possible link between victimization by violence and subsequent anti-social behavior exhibited by the victim. A 2000 Colorado State Audit of services for 306 people with developmental disabilities who were victimized and who demonstrate anti-social behaviors were reported to have the following major subsequent behaviors: (a) aggressive behavior, including assaults at 75% (229) and (b) aberrant sexual behavior, including pedophilia and paraphilia at 44% (133). Some individuals were reported to display both types of behavior (Colorado State Department of Human Services, 2000).

12. With regard to sexual abuse of persons with developmental disabilities, several studies have reported findings. Valenti-Hein & Schwartz (1995) indicated that 90% of people with developmental disabilities will be victimized by sexual abuse at some point during their lifetime. Forty percent will experience 10 or more incidents. Sobsey (1994) refers to a studies that report 39 - 68% of girls and 16 - 30% of boys will experience sexual abuse before 18 years of age. He further estimates that each year in the U.S., 15,000 - 19,000 people with developmental disabilities are raped.

Problems with current information on data about violence and children with disabilities

The previous section reviews the most quoted and referenced information about incidence and prevalence of violence against children with disabilities. Both small sample and large sample population studies have reported that children with disabilities are more frequently victimized by violence than are children without disabling conditions. But the data for both types of studies have problems that need to be addressed. Some of the studies are fraught with definitional differences, methodological errors, calculation errors, and inconsistencies in their estimates of the extent of victimization. But despite these flaws, the accumulation of estimates by a large number of studies suggest that there is a major national problem of significant magnitude.

Specifically, what are the issues with the current data about victimization? These issues may be categorized as follows: 1. Different definitions of disability and violence; 2. Different risks according to type of disability; 3. Gender and age differences; 4. Comparisons of children with disabilities and children without disabling conditions; 5. Estimates based on different types of acts of violence (physical assault, sexual abuse, bullying, deprivation of food or medication, etc.); 6. Who are the perpetrators?; 7. Cultural differences of the subject populations; 8. Matters of confidentiality that prohibit access to existing databases; 9. Reluctance of victims to respond to questionnaires; 10. Underreporting by the victim to criminal justice agencies; 11. Lack of training and sensitivity by the researcher and those who conduct interviews; 12. Accessibility of services; and 13. Lack of scientifically sound survey research design and methodology.

1. Different definitions of disability and violence

R. Simeonsson (CR) recommended that the working definitions presented by D.K. Marge and M. Marge (see Appendix E) should be used when discussing issues about disability and violence. He further explained that the working definitions were inclusive and addressed the variety of acts of violence. Because of their legislative programs and regulations, various federal and state agencies use different definitions of disability, thereby creating a problem in the ability to draw conclusions across studies. It has been reported that there are more than 40 different definitions of disability reflecting the needs and programs of various federal agencies (M. Marge, CR). The categories used to identify and define disability create a problem for survey researchers. The definition of the Americans with Disabilities Act (ADA) is the most commonly used by researchers. Because of the need for data about segments of the population of people with disabilities, some studies report on the various types of conditions under the rubric of "developmental disabilities," hearing and visual impairments, and spinal cord injuries. In the

attempt to broaden the parameters of those who are considered disabled, supporters of the ADA consider an individual disabled if they are unable to carry out one or more functions of Activities of Daily Living (ADLs).

Another problem is related to the differing definitions used by researchers to identify the destructive acts that are incorporated under the generic term “violence.” These include maltreatment, abuse, and neglect (S. Robinson, CR). P. Sullivan (CR) observed that children with disabilities are victims of multiple types of maltreatment and there are different types of perpetrators. The terms of *maltreatment, abuse and neglect* do not communicate the significance of the destructive acts being committed against the child with disabilities. P. Smith (CR) recommended that violence should be perceived as socially pervasive – it is found in all aspects of social relations. S. Brown (CR) suggested that violence is separated into three categories: violence directed against children with disabilities, violence that leads to a later disability, and violence occurring separate from the disability. D.K. Marge (CR) strongly recommended, therefore, that the term “violence” be used henceforward in place of the differing terms found throughout the literature. Violence communicates the **severity** of the act that has been committed against a victim by a perpetrator. The need to use an inclusive term was supported by D. Bross (CR) and R. Simeonsson (CR). Tyiska (1998) supported the need to identify these events as acts of violence. She stated, “Just as with many victims, violence may be defined differently for many people with disabilities. For example, the withholding of a wheelchair, thus forcing a person to slide along the floor, might be considered an act of violence. In that regard, it is important to note that many acts of criminal violence committed against vulnerable individuals, such as children, the elderly, and individuals with disabilities, are referred as forms of abuse. While the behavior is certainly abusive, using the term abuse instead of violence can serve to minimize the severity of the crime against the individual.”

For greater clarity, the term “violence” could then be qualified by other terms that identify the act that is being committed. These are:

- a. Physical violence that may include, but are not limited to, striking (with or without an object), hitting, beating, pushing, shoving, shaking, slapping, kicking, pinching, burning, unwarranted administration of drugs and physical restraints, force-feeding, and physical punishment.
- b. Sexual violence includes illicit sexual contact and unwanted touching and all types of sexual assault, such as rape, sodomy, coerced nudity and sexually explicit photographing.
- c. Emotional and/or psychological violence includes inflicting anguish, emotional pain, distress as a result of verbal assaults, insults, threats, intimidation, humiliation, bullying, teasing, harassment, and imposed physical and social isolation.
- d. Neglect includes the refusal or failure by a caregiver to fulfil any part of their obligation or duty to the child. Neglect typically refers to the failure or refusal to provide such life necessities as food, water, clothing, shelter, personal hygiene, medicine, comfort, personal safety, and other essentials of life.

e. Abandonment refers to desertion of the child by the caregiver and differs in degree of severity of violence because it could result in life-threatening situations, leading to death. At the least, it generally results in neglect of life necessities and emotional and psychological abuse.

Finally, as a point of clarification, the terms “prevalence” and “incidence” are defined by M. Marge (CR) as follows:

Prevalence refers to the number of persons who are victimized by violence at any point in time (point prevalence) or during a stated period of time (period prevalence) in relation with the total population in which the violence occurred. It is measured and reported as a quotient rate with the numerator the number of victims and the denominator the number in the total population. Therefore, if a national survey on a population of 100,000 persons selected at random reveals that 3500 persons with disabilities were victimized last year, the prevalence rate is 0.035 (or 3500 per 100,000 or 35 per 1,000 rate). The prevalence rate provides an estimate of the number of cases in the population at present. It should be used to determine scope and magnitude of the current problem. It should not be used to estimate future outcomes. The incidence rate is the best estimate of new cases that may develop given certain factors, such as interventional programs to prevent the occurrence of violence.

Incidence refers to the number of new cases of victimization by violence that occurred during a specified period of time within the total population under study. It is measured and reported as a quotient rate with the numerator the number of new cases during a defined period of time (e.g., month, year, years) and the denominator the number of persons in the total population under study. It is usually expressed as cases per 1,000 or 100,000 per annum. Therefore, if a national survey on a population of 100,000 persons identifies and reports that 800 new cases of victimization of persons with disabilities occurred during a 12 month period, the incidence rate is 0.008 (800 per 100,000 or 8 per 1,000). The incidence rate is the best predictor of the expected increase in the population of those who have been victimized by identifying the number of cases that should be added to the existing population of victims. Both statistics, prevalence and incidence rates, allow the public health and criminal justice planners to focus their attention on both the prevalence (existing number of cases in the population) and most significantly, the incidence (the number of new cases that will be added each year). An effective prevention program will direct its energies on the reduction of the incidence rate.

2. Different risks according to type of disability

A number of studies have demonstrated that different types of disabilities are associated with differing degrees of risk for exposure to violence. For example, Dawkins (1996) reports that children with visible disabilities (such as children with cerebral palsy or visual impairments) are twice as likely to be bullied than children not associated with visible physical conditions who are enrolled in special education classes. Sullivan (2002) adds that children with disabilities are at varying risks according to their type of disabling condition – behavior disorders seem to be at increased risk for abuse, whereas children with conduct disorders are at risk for neglect. Many studies do not acknowledge these differences. A national survey should include children

with cognitive disabilities and hearing impairments in order to be inclusive of all children with disabilities (E. Briggs, CR). P. Smith (CR) indicated that it is important to examine demographics about disability by looking across and within disability groups, especially those in residential centers.

Some observers suggested that what others identify as unique risks for children with disabilities may be invalid. M. Alexander, (CR) suggested that violence may be directed to a child not because he or she is disabled but because he or she is a child. This implies that the focus should be on violence against all children and not a specific sub-group.

3. Gender and age differences

In order to understand the outcomes of violence against children with disabilities, the factor of gender can play an important role and needs to be addressed. For example, in a study by Sullivan and Knutson (1998) of 39,000 hospital records, there were slightly more males (56%) than females (44%) who were victims of violence. More data are needed to determine if this ratio is representative of the U.S. population. Another important estimate relates to victimization of children at different age levels. Are there differences according to age and if so, why? In one study on child victims with disabilities in two different settings – residential and hospital, the median age of children in the residence was 3 years, 8 months and the median age in the hospital was 4 years, 8 months. Two factors are offered to explain the age difference of exposure to victimization. One reason given is the environment, because it appears that residential settings place children at greater risk for exposure to violence. The other reason is the background and characteristics of the child who is placed in a residential setting in contrast to a child seeking pediatric services in a hospital setting (Sullivan and Knutson, 1998).

4. Comparison of children with and without disabilities

Many studies of children with disabilities who are victims of violence do not provide estimates about scope and magnitude based on comparisons with children without disabilities. Comparisons of children with disabilities with children without disabling conditions are necessary in order to determine if there is a significant difference and if so, why? For example, Goldson (1998) reported on a national study of children with and without disabilities. The prevalence rate of exposure to violence for children with disabilities was 35.5 per 1,000 compared to children without disabilities who had a prevalence rate of 21.3 per 1,000, indicating the noticeable and significant difference in exposure to acts of violence. S. Brown (CR) remarked that children with disabilities who may be victimized should be studied in all school environments. He estimates that 45% of children with disabilities are being educated in regular classrooms; therefore, violence should be studied there as well as within special education classes. D.K. Marge (CR) observed that playground activity should be included in assessing victimization, such as bullying and exclusion from play activities.

5. Estimates based on different types of acts of violence

On the assumption that children with disabilities are subject to multiple types of violent acts, such as physical abuse, sexual abuse, and emotional and psychological abuse, information about what proportions of the population are victimized by different acts of violence is important to the development of an effective national prevention strategy. National surveys about children

with disabilities who are victims of violence should include information about the type of violence and the severity of the violence. For example, reported differences of types and severities of acts of violence in a study by Sullivan and Knutson (1998) provided valuable information about the numbers of children exposed to four types of violence – neglect, physical abuse, emotional abuse and sexual abuse. D. Bross (CR) added that “sub-abusive violence,” such as number of times children have been hit, bitten and slapped, should be included in national surveys.

6. Who are the perpetrators?

A national survey about violence and disability should provide information about the perpetrators in addition to data about the victims. E. Briggs (CR) indicated that frequently it is the caretaker who is the perpetrator. S. Walker and M. Curry (CR) agreed that frequently health care providers or caregivers are the perpetrators. S. D'Eusanio (CR) reported that persons with disabilities are intimidated into silence by caregivers whom they believe will withhold services from them. In a study on developmental disabilities and sexual violence, Baladerian (1991) reported that the predator is most likely known by the victim, such as family members, acquaintances, residential care staff, transportation providers, and personal care attendants. It is possible, according to Petersilia et al. (2001), that crimes against persons with disabilities may be perpetrated by others with disabilities. They offered two reasons: (a) the initial violence may trigger the cycle of violence against others, and (b) some disabilities may result in reduced impulse control, such as witnessed in traumatic brain injuries.

7. Cultural differences of the subject populations

In order to understand the scope and magnitude of the problem of violence against persons with disabilities, in addition to the previous variables, it is important to examine the estimates of exposure and risk on the basis of minority status, religion, and socio-economic factors. These cultural factors provide further in-depth information about the practices, expectations and mores of other cultures within the greater American culture. For example, conferees commented on how cultures have different definitions of abuse of children. Slapping or hitting a child may be defined as abusive in the greater American culture but not in a minority culture that considers such behavior as a normal part of child-rearing and discipline. An important sub-culture in the United States is represented by deaf and severely hard-of-hearing individuals. Their culture uses a special language relatively unknown to most Americans, has its own mores and expectations, and demonstrates a strong sense of advocacy for preservation of their culture.

8. Matters of confidentiality that prohibit access to databases

One of the major roadblocks to determining estimates of victims with and without disabilities is the issue of confidentiality of information protected by data gathering agencies. There is an obvious conflict between the need to know and the need to protect. Many experts in the area of confidentiality of data are seeking ways in which information may be accessible without identifying the subjects. Also, the sensitivity and concern by institutional review boards may be a serious roadblock to designing and implementing important surveys. Finally, the need for informed consent is legally and ethically necessary but in some instances is the reason why selected subjects

will withdraw from a study. Some researchers believe that a certain bias in subject selection is imposed by the consent form. In such instances, it behooves the survey researcher to inquire about why an individual withdrew from a study so that reasons for lack of cooperation are understood and compared with the reasons why a subject decided to participate in the study.

9. Reluctance of victims or their parents to participate in studies and surveys about violence and disability

Even though a researcher may guarantee in writing that the information obtained in a study is confidential and will not be shared with others but reported as grouped data, some parents of children with disabilities still may be reluctant to cooperate. They fear that reports of violence against their children may expose them to legal ramifications, such as further reporting to the authorities and investigations about their own child-rearing behaviors. Another reason for reluctance of reporting was identified by J. Wildy (CR). She indicated that some persons with disabilities may not even realize they are being victimized since it has been part of their lives from early childhood, or they are mentally impaired and may not recognize the act of violence.

Another issue is the psychological impact of inquiring about an act of violence. The victim may still be suffering from post-traumatic stress disorder and review of the act and its consequences may result in further deleterious effects on the child and the family. The study of violence and disability, therefore, becomes a problem if subjects of the study are victims and need to be interviewed.

10. Underreporting by the victim to criminal justice agencies

The shame and fear that follow victimization may prevent the victim from reporting the act of violence to the authorities for a number of reasons. Although this is not an exhaustive list of reasons for underreporting, the following are among the reasons often given. First, if the victim is related to or well acquainted with the perpetrator, there is a reluctance to report the incident to the authorities. Second, as was mentioned earlier, for whatever reason or reasons (such as mental retardation, traumatic brain injury, or emotional disorders where capacity to understand is compromised) victims may not recognize the perpetrator's actions as acts of violence and necessary to report. Also, due to prior unsuccessful experiences to report when the authorities ignored the attempt and dismissed it, the victim is hesitant to approach the criminal justice system again. Finally, there are cases where the perpetrator has imposed fear and threats of retaliation against the victim and his or her loved ones if the victim reports the crime.

11. Lack of training and sensitivity by the researchers and those who conduct interviews

Many researchers in disability are knowledgeable and sensitive about issues related to disability but untrained about the significant problems that are added when any individual becomes victimized. It becomes critical, therefore, that researchers who wish to conduct studies and surveys about disability and violence need to be knowledgeable and sensitive about the nuances of each area. R. J. Weber (CR) commented that "children with disabilities experience a different kind of abuse with unique characteristics that are important to review."

12. Accessibility of services

J. Panko-Reis (CR) stated that a survey researcher may encounter resistance from service providers who are reluctant to disclose that their facilities and services are not accessible and do not provide adequate accommodations.

13. Lack of scientifically sound survey research design and methodology

Many of the large scale population studies that are reported in the literature are flawed by problems in research design and methodology (Sullivan, 2002; Petersilia et al., 2001; Bross, 2002). For example, in the study of the incidence of child abuse among children with disabilities and the relationship between child abuse and disabilities by Westat (1993), the following problems have raised serious questions about the findings and conclusions: (1) reliance on opinions of child protective service workers to assess and determine whether or not a person had a disability without having training and expertise in this area; (2) reliance on their opinions as to whether or not the disability caused the abuse or the abuse caused the disability; and (3) focused only on intrafamilial abuse and excluded extrafamilial abuse which is typically found in law enforcement records. The last reason is the most troubling because it excludes an important component of reports of violence and “calls into question the validity and generalizability of the results” (Sullivan 2002).

Recommendations for improving data collection for scope and magnitude of the problem

There should be uniform definitions of disability and violence used by all national surveys so that cross-walks between surveys and grouped analyses are valid and reliable (K. Henderson, CR). There are many problems in attempting to mesh current and planned databases that use different definitions, different aspects, survey designs and methodologies. P. Sullivan (CR) indicated that children are not victimized in “neat categories,” so the categories that are used must be inclusive and explained. She also suggests that whenever a retrospective study is pursued using reports of victimization, a statistically appropriate sample of the reports should be studied in depth by examining the records for validity and reliability.

Although anecdotal reports should not be the basis for determining estimates of victimization or predicting outcomes, they do serve the purpose of providing hunches and potential areas of future research and should not be discounted (M. Marge, CR).

As a means to improve the databases, M. Alexander (CR) supported focused and direct observation of a discrete, definable, statistically distinct population rather than review of records, such as police reports. He suggested that observational studies will provide better data than retrospective inquiry of the victim.

The development of a national survey of children with disabilities who are victims of violence should be ongoing (annual or every other year) and will require the identification of substantiated questions, instruments, and procedures that will meet the purpose of the survey with a high degree of reliability and validity. If there are areas of important inquiry that still need to be examined, further research will be required before the areas are included in the national survey. For example, M. Jonson-Reid (CR) suggested that surveys include questions about parent education programs by service providers and the potential victimization

of children with disabilities by special education and child welfare agencies. As another example, if one of the purposes of the survey is to identify the specific characteristics of the perpetrator, the survey must access data sources that may not be easily obtained. In such instances, further research is necessary and when solutions are found, they will be incorporated in future versions of the survey. The survey, therefore, is an evolving program of data collection and analysis that utilizes only scientifically-sound methodology and content (M. Marge, CR).

K. Biernath (CR) indicated no data source exists nationwide that reports death of children with disabilities due to violence. The CDC National Violent Death Reporting System will be initiated soon but will not include children with disabilities. She urged that conferees at the National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities (2002) strongly recommend to CDC that violent death among children with disabilities be included in the data set.

Finally, R. Beavers (CR) recommended that surveys should inquire if the person with disabilities was victimized by a random crime or was targeted because of his or her disability, i.e., a hate crime.

Current Statistical Findings about Adults with Disabilities

The following information about the scope and magnitude of the problem for adults with disabilities was gleaned from a comprehensive review of the information in the clinical, research, and survey reports in the same manner that was used to provide the most current findings for children with disabilities. The most significant findings are:

1. Sobsey and Doe (1991) studied sexual abuse and assault against hospitalized children and adults with disabilities. A sample of 162 case reports were examined and revealed that the mean age of the victims was 19.2 years with a range from 18 months to 57 years. It was also reported that the majority of the victims were female (81.7%) and the majority of the perpetrators were male (90.8%). Although the study contained a number of limitations, such as not providing information about operational definitions or instrument development, it is still important in highlighting the increased risks faced by persons with disabilities. In a review of the literature reported by Sobsey, it was estimated that people with disabilities experience victimization by crime four times greater than people without disabilities. Sobsey personally believes that the accurate figure is between five and ten times greater (Sorenson, D., personal communication from D. Sobsey, April 1996, CAVNET Document Number 2487).
2. Nosek et al. (1997) in a national survey of 860 women (439 with disabilities and 421 without disabilities) concluded that the prevalence of physical, emotional or sexual abuse was the same for both populations (62%). However, analysis of data about women with disabilities, in contrast to the comparison population in the study who were without disabilities, revealed "a significantly greater number of perpetrators and a significantly longer duration of abuse." In further analysis, Young et al. (1997) found that women with disabilities were more likely than women without disabilities to be subject to violence by attendants and health providers.
3. In a study of 171 confirmed reports of sexual abuse of adults with mental retardation who are residents of Connecticut, Furey (1994) found that the

women comprised the majority of the victims at 72%. Similar to the findings of Sobsey and Doe, Furey found that the majority of perpetrators were male (88%).

4. Brown et al. (1995) studied sexual abuse of 109 cases of adults with learning disabilities living in staffed housing. They found 85 (78%) confirmed cases of sexual abuse. Unlike previous studies, this study found that males were abused in the same numbers as females although the majority of the perpetrators were males. These data are important because they provide information about violence against male and female victims.
5. In 1990, Ulincy et al. studied persons with disabilities who were victimized by their attendants. They interviewed 91 participants by phone to explore theft and physical abuse by their hired attendants. Of the 91 cases, 36 or 40% reported theft and 9 or 10% reported physical abuse and theft.
6. Powers et al. (in press) conducted a study of 200 women with disabilities from the Portland, Oregon, San Francisco Bay area, Chicago and St. Louis to assess personal assistant services abuse. Of particular significance was the finding related to repeated episodes of abuse by any perpetrator throughout the individual's lifetime. It was revealed that 67% of the women experienced lifetime physical abuse and 53% of the women experienced lifetime sexual abuse. These estimates are twice the rate experienced by non-disabled women (National Research Council, 1996).
7. Harrison-Felix et al. (1997) studied the differences between persons with violence-related traumatic brain injuries (TBI) and those with nonviolence-related traumatic brain injuries who received rehabilitation treatment between 1989 - 1996. A study population of 803 individuals were divided into two groups according to violence-related and nonviolence-related categories. It was revealed that 234 (29%) individuals had violence-related TBIs whereas the remaining 569 (71%) had nonviolence-related TBIs. Of those with violence-related TBIs, 86% were males and 14% were females. Also, they were generally non-white, unmarried, living alone, less educated and not employed.
8. The National Elder Abuse Incidence Study (NEAIS, 1996) conducted by the Administration on Aging was the first attempt to estimate the number of elders abused or neglected during a particular year in the United States. The total number of elders (60 years and older) in domestic and institutional settings in 1996 was estimated at 43.9 million. The NEAIS examined reports from Adult Protective Services (APS) state agencies with the exception of Hawaii, Alaska, and the U.S. Territories. The best national estimate is that the total of 551,011 (1.25%) elderly persons, aged 60 and over in domestic settings, experienced abuse, neglect, and/or self-neglect in 1996. Of this number, 115,110 (21%) were reported and substantiated by APS agencies. The remaining 435,901 (79%) were not reported to APS agencies. The conclusion is that 3.8 or almost four times as many new incidents of elder abuse, neglect, and/or self-neglect were unreported. The standard error, therefore, suggests that nationwide there is a range of estimates from 314,995 to 787,027. The categories of abuse included physical, emotional, financial, neglect, abandonment, and self-neglect. Of particular interest to the researcher in disability and violence is the finding that 51.9% of the elderly were described either as somewhat able or not able to take care of their physical needs. This

suggests a high rate of physical frailty among the victims when compared to a 20% estimate of disability in the general population. Also, 9.6% - 12.6% of the elderly were judged to be depressed. Furthermore, 45.5% of the victims were judged to be confused some of the time or very confused. The judgments were made by the observers in the study and were not the result of mental impairment testing. Nevertheless, if one were to extrapolate from these national data, it appears that the problem of violence against elders with and without disabilities is another dimension in the determination of the scope and magnitude of the problem.

Problems with current information on scope and magnitude on adults with disabilities

The issues discussed about the limited information on estimates of the problem of violence against children with disabilities are approximately the same as those found for adults. These problems identified were derived from the literature and the observations of the conferees, as follows:

1. Different definitions of disability and violence

The issues that were cited in the section on Children with Disabilities are the same issues that pertain to the literature on Adults with Disabilities. Existing data bases and studies are limited and use a variety of definitions of disability that result in considerable difficulty in interpreting information from these studies. In the same manner, definitions of violence against adults are inconsistent and often unexplained. M. Turk (CR) stated that there is a need to have consistent definitions of disability and violence-related items. These inconsistencies render the interpretations of the data at risk. The literature abounds with different terminology which appear to fall under the rubric of violence. They include the terms, abuse, crimes, and neglect. Nosek et al. (1997) refers to emotional, physical and sexual abuse. Sobsey and Doe (1991) studied sexual abuse and assault against hospitalized individuals with disabilities. Furey (1994) also focused on sexual abuse as did Brown et al. (1995). Ulincy et al. (1990) makes reference to victimization by physical abuse and theft. And, Powers et al. (in press) refers to abuse. Among the authors cited who use the generic term "*violence*" are Harrison-Felix et al. (1997), Tyiska (1998), and Petersilia et al. (2001).

Although a number of researchers indicated that their data base was national, they did not meet the essential requirements of a large scale population study that could provide estimates of the magnitude and scope of the problem.

2. Different risks according to type of disability

According to Petersilia et al. (2001), people with disabilities risk varying degrees of victimization according to their disabilities. Much of this information is based on published anecdotal evidence or small sample studies. Sobsey and Doe (1991) reported that women with intellectual disabilities (83% of their sample) had been victims of sexual assault. In a study of women with physical disabilities, Nosek et al. (1997) found no differences in the percentage of women with and without disabilities who were victims of emotional, physical or sexual abuse.

M. Dubin (CR) indicated that most of the data come from the developmental disability service systems. These reveal that persons with developmental disabilities are likely to be raped more than ten times in their lifetime and there are few studies about people with other disabilities.

3. Gender and age differences

Petersilia et al. (2001) contended that no data are available to document assumed high rates of abuse of men and boys with disabilities from caregivers.

4. Comparison of adults with and without disabilities

It was estimated by Sobsey et al. (1995) that compared with other people, individuals with developmental disabilities are 4 to 10 times more vulnerable to crime victimization.

Wilson and Brewer (1992) found that adults with intellectual disabilities had greater rates of victimization when compared to adults without disabilities as follows:

3 times greater for crimes of assault and 11 times greater for crimes of sexual assault.

5. Reluctance of victims or their parents to participate in studies and surveys about violence and disability

J. Wildy (CR) felt that people with disabilities would not answer questions in a survey accurately because they might not have full knowledge about identifying abuse or because they were afraid of the consequences of reporting the answers. Victims might also be unsure that their information would be treated in a confidential manner or there might be someone with them who would overhear their responses when they answered the survey. S. D'Eusanio (CR) concurred that persons with disabilities may be intimidated into silence by caregivers whom they believe will withhold services from them. Some conferees felt that the survey might not be inclusive of people with cognitive disabilities, those with short-term memory problems, or persons with hearing or other sensory impairments. M. Curry (CR) suggested that women may not report abuse to protect their children and to prevent them from being taken away.

6. Underreporting by the victim to criminal justice agencies

The Bureau of Justice Statistics (2000) indicated that among all populations, only 37% of all crimes that were committed were reported to police. Reports of sexual assault are even fewer because it is a "stigmatized" crime. It is suggested that persons with disabilities would not likely report most of the violence they experience.

Wilson and Brewer (1992) concluded that people with mild mental retardation underreported 40% of their criminal victimization. Persons with severe mental retardation underreported 71% of their criminal victimization.

D. Kissel (CR) noted that one of the problems with underreporting of violence is the fear of repercussions and the punitive nature of the situation. One aide may be afraid to report another and schools may be afraid to lose licensure. A parent may be afraid that the school will force her to take her child elsewhere. These reluctances result in perpetuating a cover-up. Kissel suggested that a mechanism be created that eliminates fear of reporting incidents of violence. One way this can be managed is to establish a Victim's Services Board that will accept calls about victimization from anonymous callers.

7. Lack of training and sensitivity by the researchers and those who conduct interviews

R. Beavers (CR) indicated that a reason victims of violence may not be reported as being disabled is “lack of sensitivity of law enforcement.” If a victim has a disability that is not obvious, police will not ask about the type and extent of disability during the development of a criminal report or investigation. M. Calvey (CR) reported that more than 60% of women in the domestic violence shelter in which she works have a disability with at least 50% of the disabilities resulting from the domestic abuse. Also, she stated that 35% of the women in her shelter have suspected traumatic brain injuries related to the violence. Even with these numbers, there is no standardized training program for employees who conduct interviews and keep records of their residents. R. Hughes (CR) has developed a guidebook on disabilities for domestic abuse programs and for Centers for Independent Living. And, M. Curry (CR) reported on her attempts to include questions about victims with disabilities on police reports but was unsuccessful because of “legal considerations.”

8. Lack of scientifically sound survey research design and methodology

In addition to the need for development of consistent definitions and terminology, M. Turk (CR) recommended the need to identify barriers related to reporting, to develop valid and reliable statistics, and to apply methodological and scientific rigor.

Recommendations for improving data collection for scope and magnitude of the problem

In planning and implementing a national ongoing survey that provides reliable and valid estimates of disability and violence, a number of excellent recommendations were made by the participants at the National Conference. With regard to obtaining information from all pertinent agencies that provide services to people with disabilities, J. Cyril (CR) recommended that hospital surveillance forms that monitor spinal cord and traumatic brain injuries at the time of admittance should include a question about what caused the current disability – was it the result of violence by a perpetrator or an unintentional act of violence, such as a fall or an automobile crash?

M. Overpeck (CR) reported that the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA/HHS), is in the process of standardizing data collection and definitions for public health purposes. For example, the Pediatric Trauma Registry assesses children who are victims of violence and determines the level of the child’s disability from the moment of intake. Currently, the Registry collects information about children in institutions that service children with acute trauma.

Because of the overwhelming anecdotal evidence identifying the significant numbers of refugees who have been victims of violence, A. Gray (CR) recommended that it is important to include the population of refugees with disabilities in data collection efforts.

L. Myers (CR) referred to an inability to persuade domestic violence shelters to identify and report victims of violence who are disabled. There is a lack of education and training, even among disability service providers, to ask if there is violence or a history of abuse.

According to R. Beavers (CR), police officers on the front lines are not being trained to effectively interact with persons with disabilities. Of particular interest is the distinction that should be made by law enforcement about the intent of the perpetrator – whether the victim was specifically targeted because of the disability. If so, the victimization falls into the category of a “hate crime.”

It is necessary to obtain statistics on when the violence occurred in order to identify the early onset of victimization (B. Frantz, CR). National surveys should include information about incident reports of violence from shelters, group homes and nursing homes. Currently, many of these facilities do not have formal reporting systems.

In the development of a national survey on violence and disability, S. Walker (CR) stated that the researcher must be sensitive to the impact of the trauma of victimization on the individual. If an in depth interview about the event is planned, researchers should delay questioning until a period of time has passed. In addition, the type of disability and intensity of the victimization should be reported. As we attempt to encourage the most thorough reporting of violence by victims to law enforcement authorities, there may be consequences faced by the victim. Steps should be taken to protect the victim from any further mental anguish, fear or victimization either intended or unintended.

It was recommended by R. Hughes (CR) that Federal agencies develop a Task Force of Interagency Representatives with members from disability groups to address the problem of better data gathering and analysis on disability and violence. S. Tingus (CR) suggested a Federal agency oversee the initiative and wants everyone to keep in mind National Institute on Disability and Rehabilitation Research’s (NIDRR) commitment to all people with disabilities. He believes that a White House Initiative (Executive Order) for the “prevention of violence against persons with disabilities” would establish a federal agency-wide commission that will look at the current level of violence and surveillance across agencies and at the state level and would provide recommendations for further reform. This commission could also include consumer participation and receive attention and resource commitment at the Federal level.

The importance of bringing together researchers who compile data or manage existing data sets from disability, health and criminal justice programs was recommended by B. Frantz (CR). The collaboration of researchers could unify efforts and create a research agenda to work with existing surveys and shape new ones. S. D’Eusanio (CR) agreed with Frantz’s recommendation but added that the establishment of the research agenda should be a priority of the collaboration. In addition, S. Tingus (CR) suggested a general survey tool that could be used by all levels to survey all persons who are victims of violence or abuse.

M. Turk (CR) suggested involving the Violence Against Women’s Office in the U.S. Department of Justice in this collaboration. Also, the Office may be interested in a national study of the problem of violence and disability and issue an Institute of Medicine type report that will have impact on the thinking of key policymakers in Washington and throughout the Nation. Both B. Frantz and R. Hughes (CR) supported the recommendation that the collaborative group of researchers should be expanded to include people with disabilities who are victims of violence. J. Cyril (CR) suggested that the expected outcome from the collaboration will be a plan of action for research that links all data and tools for data collection from the Federal, State and community levels and reveal the gaps in required information.

Other recommendations included:

The need to examine not only victims but whether or not they have been or are abusers themselves (L. Davis, CR).

The use of a two pronged approach to the problem of disability and violence – (1) a national data collection effort to determine the magnitude of the problem and (2) a national initiative to provide essential services to victims while data are being collected (E. Briggs, CR).

There is a need to ask questions about disability that include people with cognitive or mental health disorders (J. Manders, CR). Two questions that have been piloted by CDC for the Behavioral Risk Factor Surveillance System (BRFSS) could be good identifiers of people with disability, according to J. Thierry (CR). C. Hoog (CR) felt that questions about all types of disability should be included in the Unified Crime Victims Survey that currently only includes questions about developmental disabilities. She indicated that surveys should also ask people with disabilities about what is needed to address the problem of abuse in addition to asking them if they have been victimized.

What was stated earlier about the various types of violence directed toward the elderly should also apply to persons with disabilities. There was consensus by the Conferees that future surveys about all disabling conditions should inquire about various types of violence to include physical, verbal, sexual, financial abuse, and disability-related abuse, such as withholding or giving too much medication, withholding equipment, or withholding of personal care.

It is important to have accessible crisis intervention services available to help people deal with emotions that may be generated when researchers ask questions about the individual's experience with violence (W. Abramson, CR). Such questions may trigger an emotional reaction, sometimes related to post traumatic stress disorder.

Questions about disability and violence should be added to the National Electronic Injury System (NEIS) that collects data on injuries that cause hospitalization (see <http://www.cpsc.gov/neiss> (N. Steorts, CR).

S. Suter and C. Decker (CR) strongly suggested that people with disabilities be involved in the process of crafting the questions and planning the survey. People with disabilities are concerned about opening themselves up to adverse results, such as loss of personal assistants, institutionalization, or guardianship, if they report. The wording of questions in any survey should minimize this problem.

Concern about the public health term, "vulnerable" was raised by C. Hoog and S. Madison (CR) because it may be perceived by the disability community as disempowering. M. Marge (CR) indicated that the term is from the science of public health that examines the degree to which any individual is exposed to a risk for injury, disease or death. The term, therefore, is not pejorative but refers to a most helpful concept about exposure of all individuals with or without disabilities and is needed for health planning. In the context of a study of violence, it would be used to identify the degree of exposure an individual or a group may encounter. It does take into account the specific characteristics of the individual or the group but also the social and environmental context in which disease, injury or death may occur. It is neutral and does not assign blame to the individual, group, social and environmental context and therefore, should not be interpreted as a term that is demeaning or disempowering. The term is used in

association with degree of risk. For example, all individuals, not just persons with disabilities, are vulnerable to street crime if they venture out into a high crime area after dark. In this circumstance, the high risk or vulnerability is related to the environment and does not focus on the strengths or weaknesses of the individual or group. It is possible to assign a greater degree of vulnerability for injury or death if the individual has a spinal cord injury and is in a wheelchair on the 60th floor of a skyscraper during a fire that engulfs the building. Even if precautions are taken to assist the individual in escaping such a catastrophe, the circumstances are such that the individual is vulnerable for injury or death. Others without disabilities are also vulnerable but may have a better opportunity to escape.

Telephone surveys should be supplemented with face-to-face interviews, especially for people with cognitive disabilities (L. Powers, CR). Powers added that the information from a survey about violence and disability could be used to empower rather than disempower the individuals. "We walk a tight rope by raising the issue of increased risk and making women look victimized." In addition, it is necessary to assess the audience and how the data will be interpreted and utilized.

It should be noted that the National Institute on Disability and Rehabilitation Research (NIDRR) has established an Interagency Committee on Disability Statistics which is reviewing every federal survey being proposed (B. Berland, CR). Berland recommended that this Committee should take steps to insert questions about violence and disability in pertinent Federal survey research efforts and recommend that people with disabilities should be oversampled in general surveys because of the low prevalence of the population.

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CHAPTER FOUR:

WHAT ARE THE WAYS PEOPLE WITH DISABILITIES AND THEIR FAMILIES COPE WITH VIOLENCE?

A major question asked by researchers in public health and law enforcement concerned with violence prevention and intervention against persons with disabilities is how well do victims and their families react to and manage episodes of victimization by violence? To answer this question, a careful examination of the literature and the observations of the conferees are reviewed here. This Chapter is divided into two sections: Perspectives on Children with Disabilities and Their Families and the Perspectives on Adults with Disabilities.

Perspectives on Children with Disabilities and Their Families

This section addresses the following issues: 1. Victims' response to violence: Denial and other psychological reactions; 2. Double victimization; 3. Programs to assist victims to prevent revictimization: Protective skills development; 4. How families cope; 5. Secondary victimization; 6. Community support systems; 7. Awareness and sensitivity training of providers; 8. Ideal interventions for children with disabilities; and 9. Need to support prevention programs.

Victims' response to violence: Denial and other psychological reactions

According to Sullivan (2002), depending on the type and severity of the disability, some children who have been victimized think every contact is violent. There are anecdotal reports about children with mild or moderate intellectual deficits who experience violence and as a result develop immense fear and post traumatic stress disorder.

In one case, the victim became extremely fearful about going outdoors or being alone in the neighborhood and has become socially isolated and withdrawn. Prior to her victimization, she was notably social and outgoing. She is now distrustful of others, particularly men who resemble her perpetrator.

Some children with severe intellectual deficits or psychopathologies may not understand the gravity of their victimization. P. Smith (CR*, 2002) identified a program in Vermont that provides appropriate communication supports in the court system to assist people with disabilities in helping them understand what is transpiring. Although it was difficult to persuade the courts to provide this service, now that it is in place, it has proved to be very successful.

K. Biernath (CR) observed that victimization increases the child's risk for subsequent behavioral problems, such as drug abuse or perpetrating violence upon others. Bross (2002) supported this observation and reported that children who are victims of violence might develop aggressive, delinquent or criminal behavior in later life if effective interventions are not instituted early after victimization. For example, two groups of mothers who had propensities for using physical acts of violence in childrearing were studied by Olds et al. (1986, 1997). The first group of mothers received training on controlling and reducing their violent behavior. The second group was a randomly selected control population which did not receive the special parental training. It was concluded

*CR means "conference remarks" made by conferees during the National Conference on Preventing and Intervening in Violence against Children and Adults with Disabilities," May 6 and 7, 2002.

that the early intervention and training with mothers resulted in reduced risk for subsequent delinquent behavior and reduced potential for arrest of their children when compared with the control group. Although the children studied did not have disabilities, one can extrapolate this successful finding to children with disabilities who are victimized.

Another consequence of victimization of children as mentioned by D. Bross (CR) is that the victim in adulthood may experience parenting difficulties with their own children.

Double victimization

Sullivan (2002) provided another perspective about children with developmental disabilities who were victimized and later committed crimes, leading to incarceration in detention centers. She found that many of the children in such circumstances became revictimized in the detention center – an example of double victimization.

Commenting on the possibility of double victimization, D. Kissel (CR) presented another perspective. When parents try to cope with the victimization of their children and are not supported by the legal or school systems, their children become victimized twice. First the child is victimized by a perpetrator and then the system ignores their pleas for due process and victimizes them again. For example, if a parent suspects that an aide is perpetrating violence against her child, she may face considerable “red tape” and not receive cooperation from the schools because of fear of litigation. Kissel suggested that parents of children with disabilities become involved in parent-related school activities so that the school will become aware of her child’s needs and can function as an advocate in case an adverse event occurs.

Programs to assist victims to prevent revictimization: Protective skills development

M. Marge (CR) suggested that health care providers, especially rehabilitation specialists, should take into account those factors that may have resulted in revictimization and new injuries. As part of the rehabilitation process, the child should be taught how to prevent further victimization now and in the future.

The need for protective skills development was noted by J. Lutzker (CR). He recommended that it is important to identify the most successful protective factors and design a program of training to meet the needs for each family. For example, a person with a brain injury cursed violently and struggled with staff until he was taught stress reduction strategies that allowed him to progress to a more constructive interaction with staff.

How families cope

M. Alexander (CR) noted that almost all parents use coping strategies that they learned from their own parents, families and culture. Most parents have only observed the parenting of children without disabilities. Very seldom do people learn from their own parents how to manage children with disabilities, especially those who have been victimized. K. Henderson (CR) reported a consensus view that people with disabilities and their families, in general, do not cope well with violence. There is usually denial in the families and in the communities about violence against children with disabilities.

Sullivan (2002) also noted that parents who are perpetrators of violence will deny their role in the child's victimization. If the child is being victimized by others known to the parents, they may still deny that their child is being victimized.

With regard to attitudes about the criminal justice system, Sullivan (2002) reported that some parents are outraged by the system; some accept it because they cannot do much about it; some are fearful they cannot obtain help; while others cope with the system and report the victimization the first time but not second or third. The issue is not whether the child is believable (as a witness) but whether the county attorney decides to prosecute. M.H. Witten (CR) agreed that victims and their parents feel victimized by the criminal justice system because frequently from previous experience, no one will provide assistance.

It was speculated by R. Kornblum (CR) that the reactions to violence by families with children who are disabled and families with children without disabilities may be similar. But the need for special services for children with disabilities, however, would be different from those who are not disabled. For example, a child victim who is nonverbal will require the services of a specialist who can communicate with the child.

There are federal programs that provide resources to families who have children with disabilities. But according to D. Kissel (CR), if the child's service provider is unfamiliar with the federal support programs and the programs are not implemented, the child will not obtain the necessary protective services. Service providers should be familiar with the Individuals with Disabilities Act (IDEA), Americans with Disabilities Act (ADA), Rehabilitation Act, programs of the Department of Justice, and programs of the Administration for Children and Families in the Department of Health and Human Services, in addition to the other rules and regulations that they must follow.

As an illustration of coping, a parent of a crime victim with a developmental disability reported that after the victimization, the family had to deal with the myriad of fears resulting from the attack. To help with their coping, the family relied on a support system consisting of other family members, their friends, their house of worship and families of other children with disabilities. In addition, the family interfaced with the office of disability at a local university.

Secondary victimization

D. Marge (2003) stated, "Persons with disabilities who experience violence are not the only victims. There are secondary victims as well, those who are parents, children, family members, or caregivers of the victims. They also may experience stress, anxiety, and fear for the safety and life of the victims, as well as their own." Petersilia et al. (2001) indicated that the family will most likely become secondary trauma victims, exhibiting similar responses as described in post traumatic stress disorder, including depression, anxiety, rage, denial, and reliving the event based on what they have learned.

Community support systems

A number of children with disabilities are rejected by their parents and once family support collapses, there may not be other substitutes (D. Bross, CR). Therefore, the development of community support programs is essential. Bross further observed that there are no specialized national standards for child protective services in responding to violence towards children with disabilities. The type, quality and effectiveness of the services vary from state to state and even county to county.

Commenting on developing appropriate and effective support systems, S. Brown (CR) recommended that advocates for the disabled should establish partnerships with all providers whether or not they focus on children with disabilities. The solution in developing appropriate community support systems is to strengthen those support networks that are already in existence. They, however, will require additional information and training to meet the specific needs of victims with disabilities.

Awareness and training of health providers, social service providers and members of the criminal justice system

The literature refers to the lack of sensitivity and understanding of the needs of children and adults with disabilities by health providers and the criminal justice system.

Sullivan (2002) stated, "There is a surprising paucity of training/continuing education materials for legal professionals, judges, prosecutors, Guardians ad Litem, public defenders and police officers, on the special needs and vulnerabilities of children and youth with disabilities within the criminal justice system."

It was reported that during the competency trial of a child with a disability who was raped, the first district attorney did not know how to relate to a person with a disability and did not ask the victim the appropriate questions. The judge was ready to call the victim incompetent and "throw the case out of court." A police officer who himself was a parent of a child with a disability intervened and assisted the district attorney and judge in the determination that the victim was competent. At the final trial, a new district attorney volunteered to visit the home to become better acquainted and establish rapport with the victim. The victim was accompanied to the courtroom by an advocate from the special education department of a regional university and by her parents. The defense attorney's strategy was to confuse the victim by asking ambiguous questions and calling the victim by an incorrect name. Finally, the judge asked the victim to tell him exactly what happened. As a result, the jury of ten men and two women convicted the perpetrator.

This case highlights the immediate need to provide training for health providers and members of the criminal justice system about disability and violence. The recommendation was supported unanimously by the conferees (K. Biernath, CR). Baladerian (2002) stated that California's State Victims of Crime Program has developed a protocol for providing care to victims: The Standard of Treatment Guidelines Manual for professionals who provide psychological and psychiatric therapy. Therapists must be licensed, qualified, have training in trauma and know how to effectively provide services to children with disabilities.

Ideal interventions for children with disabilities

A number of intervention programs has been identified as worthy of review and consideration. R. Kornblum (CR) referred to a STARS Program that provides sex education for people with developmental disabilities; Second Step, a violence prevention program that is directed to both children and parents; and the Family Support Program which provides funding to families of children with emotional problems so they can access resources for themselves. S. Robinson (CR) mentioned a volunteer program called MIRACOURT which is an in-home program that provides volunteer services through case managers. M. Marge (CR)

referred to a program of CDC's Division of Violence Prevention called CEPTED that examines environmental issues that have a potential of reducing violence for the child. It was recommended that CEPTED be carried over into the school.

The treatment for children with developmental disabilities, who are more socially isolated, according to P. Smith (CR), should include developing social networks and friendships. A. Badger (CR) recommended that each community should establish parental networks as a support group comprised of families whose children with disabilities have been victimized.

Earlier P. Smith (CR) reported on the provision of communications support in court to assist the victim with a disability to understand what is taking place. The accommodation for persons with communication disorders, cognitive disabilities and other problems that result in difficulty understanding what is transpiring, appears to be essential if the criminal justice system is to function fairly for those with disabilities. N. Baladerian (CR) stated that a communication support system would also apply to medical and therapy services. She further suggested the provision of other therapies, such as music, dance and art therapy for healing.

Need to support prevention programs

It was recommended by K. Henderson (CR) that violence prevention materials should be provided to the whole school. It is important to build on the strengths of federal statutes such as the ADA and IDEA.

Mansell et al. (1998) studied children with and without developmental disabilities who were sexually victimized. The results indicated that children with developmental disabilities in the study had a poor sense of personal safety, little or no sexual knowledge, were more likely to make inappropriate sexual comments, practice self-abuse, were unkempt or dirty on a regular basis, and extremely withdrawn compared to sexual abuse victims without developmental disabilities.

Perspectives on Adults with Disabilities

This section, with its focus on the needs of adults with disabilities who become victims of violence, addresses almost all the same issues found under Perspectives on Children with Disabilities. The responses to the topics in the preceding section would apply to either children or adults. Only those subsections that contain differing responses and are adult-related are included in this section. The references are derived from the literature on disability and violence and from the comments and observations of the conferees.

Victims' response to violence: Denial, other psychological reactions and health complications

Tyiska (1998) identified the various responses by victims of violence with disabilities. Victims of violence, in general, are vulnerable to exacerbated suffering, a sense of shock, disbelief or denial that the crime occurred. These responses are often followed by strong emotional reactions, including fear, anger, confusion, guilt, humiliation, and grief. For people with disabilities, these reactions may be intensified often due to low esteem and feelings of stigmatization. The reactions of self-blame, confusion, and loss of trust identified in the general population may be exaggerated for people with disabilities. The victim's denial and avoidance of the need to cope with the aftermath may somewhat explain why people with disabilities are reluctant to report their victimization.

The National Institute of Justice conducted a study that revealed that many women did not assess their victimization as a criminal act. (J. Whatley, CR)

People with disabilities and their families cope in both negative and positive ways (E. Briggs, CR). Negative ways include denial, depression, isolation from service providers and the community, and use of drugs and alcohol. Some people become abusive to others, refuse to obtain necessary medical care, develop eating disorders, and lose jobs or independence as a result of victimization. Several of the coping mechanisms are similar to coping mechanisms used by victims without disabilities. However, coping may be significantly affected by disability-related factors, such as use of equipment or medication, or need for personal assistance. People with disabilities may cope with the episode of violence by accepting their victimization. Realizing that shelters may be inaccessible, they remain in the dangerous situation. More positive ways of coping include use of self-help activities, informal supports, internet and other web based resources, or replacing their prior support network with a more healthy support system. They may pursue their own intervention without assistance or seek counseling and/or psychiatric help that enables them to move on with their lives.

In her experience with refugee populations, A. Gray (CR) indicated that victims may live with violence because of cultural reasons. In addition, M. Calvey (CR) felt that people with mental retardation, who have been violated since a very young age, consider their victimization as normal behavior.

According to J. Panko-Reis (CR), victims who acquired disabilities because of violence have difficulty separating the violence from the disability. Persons who acquire disabilities as a result of violence, often become overwhelmed with their new disability and may not have the energy to deal with their perpetrator.

Spirituality was mentioned as an effective coping strategy that some victims used, according to H. Taylor (CR).

Because of physical assault and other forms of violence, women victims suffer adverse health consequences, according to Nosek et al. (2002). These include emotional problems, physical injuries to the face and body, sexual dysfunction, depression, chronic anxiety and tension, anxiety attacks and phobias, sleep and appetite disturbance, headaches, backaches, skin disorders, genitourinary problems, suicide and homicide. In addition, there may be exaggerated feelings of guilt and shame with lower self-esteem and feelings of worthlessness. These result in poor body image, self-destructive behavior, including self-mutilation.

Community support systems

The majority of services, according to E. Briggs (CR), is reported to be inaccessible to people with physical, sensory, cognitive and speech disabilities and is not culturally sensitive to serve people with disabilities.

Funding for psychological counseling for crime victims with disabilities is available through the victim's assistance programs in every state. It has been noted by Baladerian (2002), however, that only 10% of the victims request assistance from this program. There should be more information and encouragement to utilize the victim's assistance programs, especially directly after the victimization.

Peer support is a significant approach to helping victims to cope with their victimization. A peer support group in a controlled environment, allows the victims to safely share their feelings and experiences. According to B. Frantz

(CR), men were quite open about sharing their experiences, not only as a victim but also as a perpetrator, in mixed gender or same gender therapy sessions.

There is a need for counseling and therapy for all victims of crime, L. Davis (CR), recommended. Qualified therapists and counselors, however, are not always trained to work with persons with disabilities.

There are victim service providers, according to S. D'Eusanio (CR), who teach victims with newly acquired disabilities how to deal with their disability. However, they often do not provide much needed services for victims who are mentally traumatized by the victimization.

Each state has a sexual assault coalition and domestic violence coalition for victim services but they may not all be accessible for persons with disabilities, according to B. Frantz (CR). Although shelters may exist for victims of violence, J. Panko-Reis (CR) noted that not too many are accessible for persons with disabilities. It was suggested by S. D'Eusanio (CR) that government funds from VOCA (Victims of Crime Act) and the Crime Victim's Fund as well as VAWO (Violence Against Women's Office) of the US Department of Justice could be obtained by many shelters. Perhaps mandates regarding accessibility could be stipulated as part of the requirements for the shelter grants.

J. Panko-Reis (CR) recommended conducting a survey of existing programs and resources for persons with disabilities and victims of violence. A booklet of service providers was created by R. Hughes (CR) and she recommended that others develop a similar source of information. S. Tingus (CR) suggested that NIDRR would be interested in supporting this survey along with CDC. The Department of Labor, especially the office of Disability Employment Policy (ODEP) also has an interest in this topic (J. Wildy, CR).

Awareness and sensitivity training of providers

The Office for Victims of Crime is working to educate first responders to violence, according to S. D'Eusanio (CR). Victim service providers revealed their lack of knowledge about how to effectively interact with persons with disabilities, reported B. Frantz (CR). H. Rouso (CR) remarked that it is necessary to fill this knowledge gap and increase the quality and skills of service providers for victims of violence with disabilities. A related training resource is the guidelines for training program staff in battered women's programs that were developed by The National Coalition Against Domestic Violence (1996).

Ideal interventions for adults with disabilities

A national data base of battered women's programs is maintained by the National Domestic Violence Hotline (Voice: 1-800-799-7233; TTY: 1-800-787-3224) that provides information on the architectural accessibility and availability of interpreters for these programs (Nosek et al., 2002). In addition, the National Coalition against Domestic Violence has guidelines based on the Americans with Disabilities Act for developing accessible facilities that provide services for women who have been victimized by violence.

In order for victims with disabilities to be effectively served by the criminal justice system, there is a need to provide full accessibility to court houses, police stations, rape crisis centers, and all buildings that provide services for victims (Baladerian, 2002).

Vertical prosecution is an extremely beneficial way to assist persons with disabilities through the legal system, according to L. Davis (CR) and supported

by Baladerian (2002). This is when an attorney from the prosecutor's office is assigned to a case and continues to advocate for the victim through all stages of the criminal justice system. B. Frantz (CR) concurred that this procedure is very effective.

Elements of an ideal intervention were delineated by B. Berland (CR). The system should be consumer directed and consumer responsive. It should offer choices, which includes remaining in the home and having the perpetrator removed. Intervention should be non-punitive, which means not being forced into an institution. Accessible facilities should be available in the community. Services should be individual, flexible and focused upon empowerment. Cross training should be based upon a team approach, including police, disability service providers and advocates, and crisis staff among others.

An example of this type of "ideal intervention" was described by W. Abramson (CR). At a battered women's shelter in Austin, Texas, 20% of the bedrooms and all common areas are accessible. There are visual alarm systems for women who are hearing impaired and an accessible "safe room" for women who have been raped. One staff person is a counselor who uses a wheelchair and who herself has survived abuse. Shelter staff engage in outreach programs to many groups of people with disabilities, service agencies and special education personnel within the community.

E. Briggs (CR) reported that an ideal program would have the capability to recognize victimization in people with disabilities and would expend significant resources on barrier removal and outreach. There would be accessible emergency response systems available 24 hours per day that would include emergency personal assistance services (PAS) and transportation. These systems would collect data on people with disabilities who use their services, broken down by disability type.

Need to support prevention programs

It was recommended by Nosek et al. (2002) that in order to provide effective and comprehensive community prevention programs to reduce violence against women with disabilities, it is necessary to establish networks of communication among and between battered women's organizations, disability rights organizations, disability service organizations, legal defense agencies, law enforcement agencies, religious organizations and health care service systems. This network will result in raising community awareness and increase safety and protection for women with disabilities. Baladerian (2002) indicated that there is a need for a "risk reduction training program" that teaches individuals with disabilities and their families about what they can do to prevent exposure to violence now and in the future. This was reinforced by Tingus (2002).

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CHAPTER FIVE:

WHAT STEPS SHOULD BE TAKEN TO PREVENT AND INTERVENE IN VIOLENCE AGAINST CHILDREN AND ADULTS WITH DISABILITIES?

This Chapter begins with an urgent appeal to the President of the United States to issue an Executive Order to establish a Presidential Commission on Ending Violence Against Children and Adults with Disabilities. The Presidential Commission will develop a National Plan to End Crimes of Violence that includes effective programs to: A. Prevent violence against children and adults with disabilities and B. Intervene in violence when children and adults with disabilities are victimized. Under each category of prevention and intervention, specific plans, objectives, and strategies will be discussed.

An Urgent Appeal to the President of the United States to

End the Crimes of Violence against Children and Adults with Disabilities

Within the current national context of heightened awareness about public safety and protection of our citizens (e.g., Homeland Security), the President is requested to issue an Executive Order *as soon as possible* that establishes a Presidential Commission on Ending Crimes of Violence against Persons with Disabilities.

1. The charge to the Commission is to examine the problem of violence and disability, taking into account this Report and making recommendations about ending violence against persons with disabilities to the President in eighteen months from the date of the Commission's first meeting.
2. The membership of the Commission should include experts in violence and disability from the following categories—researchers, advocates, consumers, service providers and policymakers from key federal and state agencies. At least 50% of the membership should be people with disabilities.
3. In addition to staff research, the Commission should hold regional public hearings throughout the United States (such as in ten regions) to receive data and testimony from a broad public representation.
4. Topics of special concern that should be addressed by the Presidential Commission include (a) establishing a Five Year National Plan to End the Violence (Effectively Prevent Violence and Intervene in Violence against Persons with Disabilities); (b) developing a national policy agenda; (c) creating a clearinghouse on information regarding violence and disability; (d) encouraging state and local level cooperation with the National Plan; and (e) identifying the role of the New Freedom Initiative and the Olmstead Act in the National Plan.

Preventing Violence against Children and Adults with Disabilities

There are four components in the development of a national prevention program: 1. establishing a priority, 2. determining magnitude and scope of the problem, 3. creating a plan of action and implementation, and 4. instituting an evaluation system (M. Marge, 2002). These are described as follows:

Establish a priority by the Federal Government and by state and local governments to End the Violence

With action by the President to establish a Commission to develop a National Plan to effectively prevent and intervene in violence against persons with disabilities,

it is essential that state and local governments agree to cooperate with the federal initiative by participating in the development and implementation of the National Plan. Three organizations, the National Governors' Association, the U.S. Conference of Mayors, and the National Association of Counties, should be among many organizations enlisted to participate in this critical endeavor.

Determine the magnitude and scope of the problem

The Presidential Commission should begin as soon as possible to obtain the best estimates of the prevalence and incidence of victimization of children and adults with disabilities. Some of that information is contained within this Report. Based on the current review of the literature, information from current surveys, and the information presented by experts in violence and disability, the Commission should begin the process of developing the National Plan. Although the current information about the magnitude and scope of the problem is sufficient and compels the United States to proceed with an action plan to End the Violence, there are data that should be sought through the development of an ongoing surveillance system on violence and disability. In addition to estimates about the numbers of victims and potential victims, the Commission should undertake a needs assessment of required resources in order to delineate the existing gaps in the development of effective prevention and intervention programs. It is assumed that many resources are already available at all levels but there *will be* gaps that need to be filled.

Create a plan of action and implementation

The next step in the development of a National Plan is to delineate goals and objectives for reducing and/or eliminating victimization, define strategies, and identify responsible agents or agencies to implement the strategies according to a specific and reasonable timetable. The National Plan should be the product of all potential stakeholders in its development and implementation at the Federal, state, and community levels to include government officials, policymakers, researchers, service providers, advocates and persons with disabilities and/or their families. The objectives and strategies should be realistic, feasible, valid, and effective.

Specific recommendations for developing an effective prevention program include the following:

- Train children and their families in ways to reduce exposure and risk to violence. Ideally, programs should begin prenatally (D. Marge, CR*) to include expectant parents who are counseled on healthy child rearing practices (e.g. The Healthy Start Program). And, after the baby is born, continued awareness should be provided by the pediatrician and other professionals who deliver services to children with disabilities. It has been reported that some mothers with post partum depression may injure their children. A program of prevention needs to address this potential problem (D. Marge, CR). A single mom's program was mentioned by M. Jonson-Reid (CR) that allowed for frequent visitation in the early period after childbirth to provide the parent with necessary resources. Although this model did not focus on children with disabilities, it might be transferable to that population. It was suggested by P. Smith (CR) that the process of identifying resources

*CR means "conference remarks" made by conferees during the National Conference on Preventing and Intervening in Violence against Children and Adults with Disabilities," May 6 and 7, 2002.

might be overwhelming for the family of a child with disability because of the stress of day to day issues. He indicated that a resource person (ombudsperson) in the pediatrician's office might be a beginning step for identifying required services.

Provide respite care for families and other caregivers to reduce the stress related to intense caregiving (L. Baker, CR and D. Marge, CR).

- Both children and adults need to develop a sense of “empowerment” (Walker & Hearst, 2002). They define empowerment as having a sense of controlling one's destiny to a certain extent. Also, empowerment is essential to one's mental health and successful development. Pinderhughes (1983) indicated that power or lack of power becomes a critical issue in people's lives.
- As the child moves into preschool and primary grades, the prevention program must be flexible and relevant to the needs of each child. For example, children with cognitive disabilities will require special teaching strategies so that the child learns about safety and protection. Parental training should include how to assess possible risks, quality of care, and signs and signals of victimization. P. Smith (CR) recommended that families and people with developmental disabilities should control their Medicaid Waiver funding which would empower them by allowing control over whom they hire and fire. Empowerment and increasing self-advocacy is an important prevention tool. Walker & Hearst (2002) identified self-protection training and a personal safety plan that would include a safe place to stay and the best means to get there.
- Lee (2002) reported that the Office of Special Education Programs, US Department of Education, participates as an active member of the National Institutes of Health's Child Abuse and Neglect Working Group and the related Federal Child Neglect Research Consortium.
- Lutzker & Klevens (2002) recommended that young children should be taught that bullying is undesirable behavior. According to Banks (1997), “bullying in school is a worldwide problem that can have negative consequences for the general school climate and for the right of students to learn in a safe environment without fear.” Children who bully are at risk for a host of long term, negative developmental outcomes, including juvenile and adult criminal behavior (Patterson et al., 1992). Recent research indicates that among other problems, children who are bullied by age 8 are six times more likely to be criminals at age 24 and five times more likely to end up with serious criminal records at age 30 in comparison to non-bullies according to Hoover (1996), Olweus (1991), and Eron (1987). A promising training program in prevention of teasing and bullying is offered by the Wellesley Centers for Women, Wellesley College, Mass. The directors, Mullin-Rindler and D'Antona (2001), describe the curriculum as follows: research about bullying and implications for classroom practice; selected activities from curriculum guides – Quit It! and/or Bullyproof; resource and tips for successful implementation of a classroom approach; school-wide strategies to reduce bullying; and strategies for dealing with individual instances of bullying.
- M. Turk (CR) recommended that children with disabilities become educated about their rights and responsibilities related to healthy sexuality, sexual abuse and domestic violence. It is postulated that this information will help in reducing their risk for victimization. It is important to recognize all

individuals as sexual beings, noted B. Frantz (CR). Although it is important to address sexual assault, there is a need for healthy sexual experience by people with disabilities. Sexual education should be taught at a young age, and with concepts appropriate for the child's age and disability. It is critical to distinguish between healthy sexual experience and sexual violence and provide individuals with the language to differentiate between the two.

- Train caregivers, teachers, and providers of services in violence prevention. Also, work through professional associations and obtain their support for the national prevention program. According to L. Baker (CR), the ARCH National Respite Network and Resource Center in Chapel Hill, NC, conducted a national study indicating that respite care for families prevents the victimization of children, with a key element of early intervention with respite support.
- An important recommendation contributed by A. Gray (CR) was to provide training to immigrants about U.S. cultural norms on what constitutes violence and violent behavior so that they are sensitive to U.S. standards and definitions of violence.
- Institute a community-wide program to heighten awareness of the risk for child and adult victimization and how the community may assist in preventing violence. L. Myers (CR) reported that her program, IndependenceFirst of Milwaukee, Wisconsin, promotes disability awareness to service providers in conjunction with Domestic Violence Month. This program could be initiated by an organization of parents with children who have disabilities as well as parents with children who do not have disabilities to provide guidance and direction to the community-based prevention program. With regard to adults, the Institute on Women with Disabilities at Baylor University has developed and pilot tested a safety planning workshop that included consumers (R. Hughes and H. Taylor, CR). The workshop addressed types of violence, safety planning and resources. Turk (CR) recommended the creation of a speakers' bureau on the topic of disability and violence.
- Use Victims' Rights Week (usually the second to the last week in April) to publicize violence and disability issues. In addition encourage disability and health care organizations to publicize the issues related to violence and disability. These include National Council on Independent Living (NCIL), Statewide Independent Living Councils (SILC), Association of Programs for Rural Independent Living (APRIL), American Physical Therapy Association (APTA), American Occupational Therapy Association (AOTA), American Nurses Association (ANA), American Speech-Language-Hearing Association (ASHA), American Public Health Association (APHA), and Joint Commission on Accreditation of Healthcare Organizations (JCAHO). B. Frantz (CR) reported that she had no success in including disabilities in the recognition of Victims' Rights Week in her community. In response, her Institute on Disabilities in Philadelphia, PA, instituted its own End of Silence Awards which received recognition from the State Government. Through this effort, the Victims' Rights Week groups are reconsidering the request to include disabilities in their future campaign. Furthermore, the Institute on Disabilities is planning to expand its awards program to a national level if funding is made available.

- The Institute on Women with Disabilities at Baylor University (Houston, TX) has developed and pilot-tested a safety planning workshop that includes consumers. The program includes a video, poster and portable pocket card with advice. It addresses the types of victimization, safety planning, and resources.
- S. D'Eusanio (CR) suggested that the National Institute on Disability and Rehabilitation Research partner with the National Council on Disability on crime prevention to stimulate awareness of the issues, conduct research on the prevalence and causes of violence against people with disabilities, and develop prevention strategies.
- Another recommendation was made by K. Kirschner (CR). She suggested posting hotline and other critical numbers at various locations and displaying pamphlets in critical sites for the purpose of disseminating information to the general public. These materials should list contacts for reporting acts of violence and for requesting assistance.
- Information about community services for victims of violence should be made available to both children and adults with disabilities. D. Bross (CR) recommended that the information should be available on the internet and cross-linked with other web sites. Although J. Whatley (CR) agreed, she indicated that dissemination of information must also be done at the local level to be effective.
- Educate the media about disability and violence so that their portrayal of these topics are sensitive, accurate, and supportive of the community-wide program of prevention.
- Develop protocols for reporting violence against residents with disabilities in group homes.
- Create a federal registry of offenders.

Institute a program, process and outcome evaluation system

This system would carefully monitor the violence prevention program, and would contribute to a dissemination program that issues reports on a periodic basis about the progress and the outcomes of the national initiative. S. Robinson (CR) strongly supported the need for scientifically based evaluation of program effectiveness.

Model Program in Prevention

An example of a resource that supports prevention in each community was cited by D. Bross (CR). It is called the "Healthy Start Program" and is federally funded in 96 sites throughout the United States. The Program's Web Site (<http://www.healthystartassoc.org>) provides the following information: "In 1991, the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) funded 15 urban and rural sites in communities with infant mortality rates that were 1.5 - 2.5 times the national average to begin the **Healthy Start Initiative**. The program began with a five-year demonstration phase to identify and develop community-based systems approaches to reducing infant mortality by 50% over the five-year period and to improve the health and well-being of women, infants, children and their families.

Since its inception, the Healthy Start Program has been located in HRSA. Healthy Start is a component of the Maternal and Child Health Bureau and resides in the

Division of Perinatal Systems and Women's Health. The common principles underlying the Healthy Start program are:

- Innovations in service delivery;
- Community commitment and involvement;
- Personal responsibility demonstrated by expectant parents;
- Integration of health and social services;
- Multi-agency participation;
- Increased access to care; and
- Public education.

Healthy Start projects address multiple issues, including:

- Providing adequate prenatal care;
- Promoting positive prenatal health behaviors;
- Meeting basic health needs (nutrition, housing, psychosocial support);
- Reducing barriers to access; and
- Enabling client empowerment.

Presently, there are five main types of Healthy Start grants: Perinatal Health, Border Health, Interconceptional Care, Perinatal Depression and Family Violence.

Healthy Start programs are community-driven and located in the poorest neighborhoods in the United States. Since its initiation in 1991, Healthy Start has served hundreds of thousands of families. Over 90% of all Healthy Start families are African American, Hispanic, or Native American. Healthy Start specializes in outreach and home visiting – the surest way to reach the most at-risk women. Healthy Start focuses on getting women into prenatal care as early in the pregnancy as possible. It is generally accepted by the medical and research community that early entrance into prenatal care is the single most critical factor in improving birth outcomes.

Healthy Start has pioneered the use of women living in the community as outreach workers and home visitors. This approach has three important advantages:

- It saves money (nurses' salaries are at least twice that of a paraprofessional or lay worker).
- Minority pregnant women respond better to women who have "walked in their shoes."
- It has given real jobs to hundreds of unemployed women, particularly those on welfare.

Every Healthy Start project has developed a consortium, composed of neighborhood residents, clients, medical providers, social service agencies, faith representatives and the business community. This ensures that not just Healthy Start but the whole community is committed to fight to reduce infant mortality and low birthweight. Major U.S. cities as well as urban counties have a disproportionate number of poor and minority families living within their boundaries. Yet, the amount of federal discretionary dollars going directly to these cities and counties has decreased dramatically in the last 20 years. Healthy Start represents one of the few health and social services programs that is funded directly to the localities by the federal government."

Intervening in Violence against Children and Adults with Disabilities

The above information concerned the first component of the Presidential Initiative – the development of an effective prevention program. Now we turn to the second component, instituting an effective intervention program for victims of violence.

The elements of an effective program of intervention for those who have become victims of violence may be summarized in the following categories: 1. immediate availability of services (24 hours per day, 7 days per week), 2. qualified and licensed service providers, 3. encouragement of full disclosure, guarantee of confidentiality and informed consent, 4. accessibility, 5. comprehensiveness of services, 6. coordination of services, 7. continuity of services, 8. age appropriate services that are consumer focused, 9. training to prevent revictimization, 10. training to prevent victims from becoming future perpetrators, and 11. evaluating the intervention program. Although this is not a complete list, it does identify the most basic elements for effective intervention programs.

Immediate availability of services at the community level

The ideal intervention program should be available in the victim's locality any hour of the day or any day of the week and include emergency personal assistants services (PAS) and transportation. Since victimization occurs at random times, the victims should receive services as soon as possible after the act of violence. This will require a special response team within each community to answer calls for assistance under emergency conditions. In addition to medical care for injuries, there will be the need for law enforcement, social work, and psychological interventions.

M. Marge (CR) suggested that as part of the response system for treating victimization, a Coordinator of Victim's Services should be immediately assigned to oversee the development of a program of interventions for the victim. The program will include training, advisement, counseling, and coaching of the victim throughout the process of the pre-trial period, the court case, the period of sentencing, and the post-trial period. The community may be the best place to seek funds to support the Coordinator as well as others who provide special services for victims of violence.

In identifying the role of the Office for Victims of Crime (OVC) at the U.S. Department of Justice, Gillis (2002) stated that the mission has always been to advocate on behalf of crime victims and to lead the way in changing the attitudes, policies, and practices that have prevented them from participating fully in the justice system. OVC administers the Crime Victim's Fund which provides formula and discretionary grant funding to support direct services and compensation for victims.

N. Baladerian (CR) referred to the contributions of the Children's Justice Act. The Act provides grants to states to improve the investigation, prosecution, and judicial handling of cases of child abuse and neglect, particularly child sexual abuse and exploitation, in a manner that limits additional trauma to the child victim. This also includes the handling of child fatality cases in which child abuse or neglect is suspected. Funding comes from the Crime Victims' Fund and administered by the U.S. Department of Justice, Office for Victims of Crime. Grants are awarded by the Administration on Children and Families, U.S. Department of Health and Human Services (2001).

As a representative of the Disability, Abuse and Personal Rights Project, N. Baladerian (CR) commented that each of the states that participates in the Children's Justice Act has a task force on which there must be a person with a disability or a person representing disability issues. From that task force flows money to a program of services for children who are victimized. She suggested that everyone should learn which governmental agency administers the Children's Justice Act and who is on the task force, including the disability representative. People should participate in the task force meetings and submit recommendations about state needs for the task force's tri-annual report. By including disability issues in the report, the state program will continue to fund the necessary services for children with disabilities.

Representing the Rocky Mountain Survivors Center, A. Gray (CR) provided another resource related to trauma and post traumatic stress disorder (PTSD): the Child Traumatic Stress Initiative (Substance Abuse and Mental Health Services Administration, 2001). There are sites throughout the country where programs are being developed under this Initiative. The Initiative supports best practices with a focus on research, program development and implementation. Since this is a new program, several of the sites are looking for people and groups with which they could collaborate.

Qualified and licensed service providers

All interventional services for victimization should be provided by qualified and licensed individuals who are trained in handling victims with disabilities. The ability to manage a victim with communication problems, for example, will require well-trained and sensitive emergency staff. There are many anecdotes that describe disastrous experiences because the victim with a disability was not understood by the law enforcement official or a medical practitioner (Baladerian, 2002).

Recommendations by the Center for Research on Women with Disabilities (Nosek et al., 2002) proposed the following guidelines for providers of services for persons with disabilities: (1) train the staff on how to recognize signs and symptoms of violence against persons with disabilities; (2) when victimization is discovered, speak to clients directly and privately about their victimization and ways to reduce further victimization and danger; (3) for situations of extreme danger, the client or the service provider or both should immediately contact the police first and then adult protective services to report a *crime*, not an act of social disruption; (4) assist clients to develop a safety plan that they could follow to escape their situation should it become life-threatening; (5) the staff should document in the client's record their observations and discussions about violence and victimization; (6) plan for a follow-up session with the client to discuss the victimization; and (7) provide the client with resource information to assist them in their current and future situation.

Sobsey (1994) identified five areas that police training should include regarding victims with disabilities: "attitude training; awareness of medical and legal needs; multidisciplinary teamwork—learning how to coordinate with other agency staff who work with this population; court orientation—recognizing the complexity involved in bringing a victim to court; and specialist versus generalist training, in which some officers are given more detailed training to act as consultants in cases involving people with disabilities."

A training curriculum for law enforcement personnel developed by The Arc of the United States (1998) was described by L. Davis (CR). The curriculum teaches officers how to recognize a disability, how to most effectively communicate with and protect the rights of people with mental retardation, and how to protect themselves from lawsuits under Title II of the ADA by providing appropriate accommodations for the victim.

In addition, the Office for Victims of Crime, US Department of Justice (2002) recently released a publication for law enforcement officers called, "First Response to Victims of Crime who have a Disability."

Encouragement of full disclosure, guarantee of confidentiality and informed consent

Besides the fact that it is the law, every safeguard must be in place to assure the victim that their information is held in complete confidence. Victims must be fully informed about the risks of reporting before they consent to disclose their information to those who will play an essential role in their assistance. One of the key risks is that when an act of violence is reported and the perpetrator is identified, there is a danger of retaliation by the perpetrator. Under these circumstances there is the possibility that the victim may not wish to identify the perpetrator. This brings up a special problem in law enforcement. If the perpetrator is allowed to remain anonymous, he or she may commit violent acts against other potential victims. The responsibility of the service providers should include the encouragement of full disclosure about the act of violence, but at the same time, guarantee confidentiality of information, and provide protective services.

In preparation for the court case, Dinerstein et al. (1999) proposed that an advocate play a key role in the education, guidance, and direction of the victim's participation in the court system, especially one with training in criminal justice matters to help the victim understand how the process works. In addition, the advocate could function as a liaison between the victim and the criminal justice investigators to urge the police to modify their questions and their investigatory approach to increase the accuracy of the information and to follow through on the investigation in a serious and committed manner.

Once the case is in court, Petersilia et al. (2001) recommended that the advocate's role becomes crucial in informing the victim with a disability about what is transpiring and in protecting the victim's rights under the law, especially Title II of the Americans with Disabilities Act. Then after the trial, the advocate will continue to communicate with the victim, preparing him or her if there is need to present further testimony during the sentencing procedures and take whatever measures are necessary to protect the victim, especially after the perpetrator is released from prison.

L. Powers (CR) indicated that there are state and local laws that may be impediments to reporting violence. She cites the example of landlord tenant laws that prevent the police from evicting a perpetrator of violence and urges that these laws be reformed so that the victim is protected from revictimization. J. Panko-Reis (CR) indicated there is no recognition that lack of accessible housing is tied to the problem of domestic violence. People with disabilities have nowhere else to go if they are being victimized in their own home. Also, the rate of victimization in homeless shelters is high. Housing officials need to be part of the problem solving. According to L. Davis (CR), The Arc has looked at housing as

an underlying cause of poverty and felt some of the same dynamics might exist with violence and disability. It was suggested by J. Panko-Reis (CR) that if housing could be identified as a public health problem, then support in the form of funding and positive action may become available. M. Calvey (CR) added that women without disabilities can leave a situation, but this is not always possible for a woman with a disability. Local shelters generally do not have room for women with disabilities. Needed supports, such as attendant services, are not available. A concern was expressed by M. Turk (CR) about the fact that there is no evidence to support the removal of the victim as the correct approach—research is needed to document this recommendation. A program for people with disabilities was described by L. Meyers (CR) in which the perpetrator was removed and jailed instead of removing the victim. One shortcoming is that the perpetrator knows where the victim is living.

According to M. Curry (CR), there is a model program in Colorado in which victims of domestic violence with disabilities receive Visiting Nurses Association services through the police department if the perpetrator, who is often the caregiver, is removed from the home.

The drawbacks of mandatory reporting laws were discussed by R. Hughes (CR). In Texas, service providers must report suspected victimization of children, people with disabilities and the elderly. Because of the importance of maintaining confidentiality and protecting the victim, this law limits research opportunities. The Center for Research on Women on Disabilities at Baylor College of Medicine conducted research on an anonymous basis because women would not participate for fear of retaliation for disclosing an act of violence. The issue is how to collect good research data under these circumstances. E. Briggs (CR) does not support a mandatory violence reporting policy for people with disabilities that requires social service intervention as the first contact. Mandatory reporting under this circumstance turns a criminal matter into a social service matter and reduces the significance of the complaint. ***This has been an obstacle to having crimes reported as crimes rather than as exclusively social service issues.*** M. Turk (CR) noted that not having a mandatory reporting law could result in a different set of problems, such as not apprehending perpetrators. J. Panko-Reis (CR) reported that there is dissension among different disability factions on this issue. The need for specific reporting protocols was highlighted by L. Davis (CR). L. Burt (CR) suggested existing models for reporting crimes of violence should be evaluated for outcomes and if found effective, they should be replicated. If they are not effective, they should be replaced.

Accessibility

The Americans with Disabilities Act (ADA) requires that all medical and law enforcement services are accessible to people with disabilities. Accessibility refers not only to physical facilities but also to attitudes and procedures in the provision of services. For example, if a victim with a spinal cord injury is brought to the emergency room for a diagnosis of injuries and requires an X-ray, the attending physician and the facility, including the X-ray equipment, should readily accommodate the victim's disability. The physician should be sensitive to the fact that the victim is unable to stand for a traditional X-ray and may have to be imaged with a mobile X-ray unit. If a victim has a communication disorder, such as deafness, there should be an interpreter available who can communicate with the victim, providing valuable information to the service providers.

With regard to the accessibility of physical disabilities, the Victims of Crimes Act (VOCA) of the Crime Victim's Fund and Violence against Women's Office (VAWO) provide significant funds in support of shelter and service providers for women victims of crimes of violence. It was observed that the U.S. Department of Justice should mandate that these shelters become accessible as a criterion for funding (S. D'Eusanio, J. Panko-Reis, and L. Meyers, CR). M. Curry (CR) cautioned that such a mandate may be unrealistic because it takes time for shelters to renovate their facilities. She recommended that VOCA and VOWA request that the inaccessible shelters provide a plan for accessibility before funding is granted. Otherwise, to request that all shelters shut down operations to make renovations may "put them out of business." S. D'Eusanio (CR) recommended careful planning and strategizing so that the inaccessible shelters become appropriately renovated without "putting them out of business."

B. Frantz (CR) suggested that the statewide centers for independent living and disability advocacy groups should encourage shelters to be fully accessible and offer support to create a collaboration between victim's services and the disability community.

S. D'Eusanio and M. Turk (CR) recommended that all disability advocacy organizations should become familiar with the benefits of the Victims of Crime Act (VOCA). VOCA provides funding for training people in victims services and victim rights. D. Bross (CR) recommended that parent groups, advocates and disability organizations should seek out every opportunity to obtain funding for training and services for victims of violence. Furthermore, the executive committees that control Federal and state funds for victims of violence should have representation from the disability community in order to benefit the unique perspective of a consumer of services. The State of Colorado has a victims' coordinating committee for funding issues with representation by people with disabilities (Bross, CR). M. Dubin (CR) identified two other resources that provide victims' training and services and need special training in disability issues: the prosecutor's office and the protection advocacy system in every state. He noted a need to integrate disability advocates into criminal justice programs and vice versa. As a victim of a crime, the person with a disability is entitled to all services for which victims of crime are eligible. But the only way to learn about those services is to integrate advocacy into the criminal justice system. One could obtain those services by contacting the prosecutor's office to ask about VOCA-funded programs. Further, M. Dubin (CR) noted that protection advocacy services provide education as well as advocacy. He also noted that some attorneys in the community are advocates on behalf of people with disabilities and recommended that the disability community start networking with these attorneys who will assist them in effectively interfacing with the criminal justice system.

K. Henderson (CR) expressed concern that children with disabilities in foster families may not have access to advocacy and to parental representation in the event of victimization. It was recommended that these children should be included in the population of those who receive full services.

The following recommendations for increasing availability and accessibility of services for battered women with disabilities were described by Nosek et al. (2002): (1) modify shelters for battered women so that they are fully accessible, including barrier-free access to sleeping rooms and common areas, architectural features that comply with the ADA, visual and auditory alarm systems, available

interpreters, and TTYs for telephone communication; (2) insure that all services offered by battered women's programs are fully accessible and integrated for women with disabilities, including hot lines, individual counseling, and support groups; (3) provide or refer to legal assistance for obtaining restraining orders and managing court systems; (4) maintain statistics on the number of women with disabilities who call crisis hotlines or use other program services; (5) assist or encourage police in recording disability status in their crime reports as well as encouraging adoption of a separate category for perpetrators who are caregivers; (6) train staff on how to communicate with persons who have hearing, cognitive, speech, or psychiatric impairments; (7) staff of center should understand environmental barriers faced by women with physical and sensory disabilities when offering advice or referrals for obtaining shelter; (8) have on hand an extensive network of community referrals and contact numbers, including volunteers or other community resources for obtaining personal assistance; and (9) offer training to disability-related service providers, including independent living centers and religious institutions, on recognizing the symptoms of abuse and the characteristics of potential batterers.

Comprehensiveness of services

A key factor in the development of an effective program of intervention is the provision of total services available on a timely basis. If the victim needs emergency medical care, law enforcement intervention and social work counseling, these services should all be present at the time of the visit to the hospital emergency room. And, in the follow-up period, the same concept of comprehensiveness of services should prevail in order to provide all necessary interventions.

The Center for Research on Women with Disabilities (CROWD) produced three directories that provide valuable information for referral and training services: (1) *Serving Women with Disabilities: A Directory of Abuse Intervention Services* (Howland, 1999); (2) *Serving Women with Disabilities: A Guide for Domestic Abuse Programs* (Myers, 1999a); and (3) *Working with Abuse Survivors: A Guide for Independent Living Centers* (Myers, 1999b).

Interventions need to be applied on multiple levels, addressing the needs of children who are victims, perpetrators and/or witnesses as well as caregivers and other adults who interact with children with disabilities. *In training children and adults with disabilities to prevent victimization or revictimization, it is important for the trainer to avoid blaming the victim for the crime.* Parents, family members, and other caregivers (such as teachers, administrators and aides), need to learn better methods to handle their stress and frustration that may arise in working with persons with disabilities. Some of the methods include training in impulse control and non-conflict resolution.

In addition, K. Henderson (CR) indicated that an ideal intervention system for children would include good relationships between parents and the school system.

Coordination of services

S. Brown (CR) summarized three basic principles for intervention as discussed by the conferees: 1. one-stop shopping, or coordinated services; 2. family-centered services; and 3. delivery in a natural environment using community-based rehabilitation.

At the time when an individual is victimized, confusion and duplication of necessary services will defeat the objective to provide an effective program of interventional services. It is essential, therefore, that all elements of the interventional program of services work together in a coordinated and systematized manner to the full benefit of the victim. As an example of an effort to create a single point of entry for services sought by victims of violence, S. D'Eusanio (CR) reported on an endeavor by the Attorney General's Office in Florida. She encouraged the Centers for Independent Living (CILs) to become involved in victim services. First, she explained how the victim services field had grown since 1984. At that time, Florida had 50 people who worked with domestic violence and abused children. Now there are 1,500 service providers in victim services who represent victim or family survivors of homicide, domestic violence, sexual assault, and child abuse, as well as first response teams from each District Attorney's office. Although most crimes are not reported, a victim advocate is supplied to those that are reported. But there are knowledge gaps on the part of **victim service providers** and on the part of **disability service providers**. Most *victim service providers* know little about disability and lump all people with disabilities together in one group. *Disability service providers* typically know little about victimization.

D'Eusanio has encouraged centers for independent living (CIL) to become involved in victim services for a number of years. Recently, when CILs became eligible for victimization grants (VOCA), several applied, but were initially rejected. She advocated for the CILs and three centers were funded. The funds support a victim advocate position, outreach activities, and counseling. One CIL has streamlined the restraining order process to make it more appropriate for people with disabilities. Each state has a crime victim compensation fund, but its features may vary. Some include relocation assistance. Through these grants, it has been learned that once people with disabilities believe that help is available, they will disclose victimization.

In an effort to initiate better coordination of services for victims of violence who are disabled, M. Calvey (CR) reported that she is conducting successful cross-training with the Ohio County Mental Retardation and Developmental Disabilities Board and rape crisis centers. Personnel from these organizations are serving on working committees to learn about each others' issues.

As a caution about the expectation of easy coordination, B. Berland (CR) indicated that coordination costs money and requires effort on the part of the key players to attend meetings and to integrate services. J. Thierry (CR) added that true coordination is a sharing of staff, time, resources, and other tangible items.

Baladerian (2002) recommended that each state follow the California model of establishing a "think tank" at the state level to design an action plan for effective interventions for children and adults with disabilities who become victims of violence. She also identified a need to develop a network of therapists interested in or currently providing post-trauma services for children and families who have been victimized by crimes of violence.

Continuity of services

Victims of violence will be in need of ongoing services for a number of months and even years. Some will experience post-traumatic stress disorders (PTSD) that will require continued services long after the medical emergency, the activities of the criminal justice system, and the opportunity to regain some normalcy in the life of the victim.

Age appropriate services that are consumer focused

Service providers should have expertise in working with children as well as adults and creating a program of services that is age appropriate and sensitive to the needs of the victim (R. Simeonsson, CR).

Training to prevent revictimization

The ideal interventional program must include a component that teaches the victim how to avoid becoming revictimized in the future (Baladerian, 2002). M.H. Witten (CR) reiterated that victims should never be blamed for the victimization.

Training to prevent victims from becoming future perpetrators

In addition to training to prevent revictimization, D. K. Marge (CR) recommended that victims receive information from a new training module that includes anger management and non-violent conflict resolution techniques with demonstration and role playing. She indicated that such training is essential because of studies that concluded that many perpetrators of violence themselves had personal experience with childhood victimization.

Evaluating the intervention program

In order to determine the progress in implementing the intervention program, a program and process evaluation system should be developed. It will provide valuable information about the effectiveness of the components of the intervention program and ways in which to improve the provision of services. L. Powers (CR) recommended that an evaluation component with specific feedback from users with disabilities should be instituted.

Two Examples of Model Programs in Intervention

- a. SafePlace in Austin, Texas. W. Abramson (CR) described a battered women's shelter with 20% of its bedrooms and all common areas accessible for women with disabilities. The accommodations include visual fire alarm systems for women with hearing impairments and an accessible room for women who have been recently raped. The counselor on staff is a woman with a physical disability who has been a victim of violence. Shelter staff conduct outreach programs to many groups of people with disabilities, service agencies and special education personnel.
- b. Partnership between Connecticut State Department of Mental Retardation (DMR) and the State Police. R. Beavers (CR) reported on a successful state program that enforces DMR rules and protects persons with mental retardation. The program investigates allegations of staff crimes against residents of state homes for persons with disabilities. Incidents between residents are typically not addressed, unless a high functioning client is taking advantage of a lower functioning client in an abuse (vs. fighting) situation. If violence is suspected in the family home, the unit will help the appropriate agency interface with law enforcement. Prior to this partnership, DMR did their own internal investigations and typically did not report crimes such as

theft, sexual assault, and other acts of violence to law enforcement. Under the partnership, all criminal investigations are run by law enforcement officials. Beavers and his staff of police officers, nurses, and social workers are an autonomous unit attached to DMR. Beavers functions as a permanent liaison, informing, but not answering to, the Commissioner of DMR. If an incident has a criminal component, then DMR and the law enforcement unit conduct separate, but parallel investigations. The unit will turn over criminal cases to local law enforcement, share all of the information they have collected, and protect evidence. They also provide support to local law enforcement investigations by providing case managers and interpreters to support communications. Ten years ago, before this Program started, 100% of perpetrators returned to their jobs. Since this new program began, however, no perpetrator has been reemployed. The program sends a strong message to deter perpetrators and to help parents of residents feel more comfortable about the safety of their children. This program could also apply to group home settings for children and the elderly.

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CHAPTER SIX:

WHO IS RESPONSIBLE FOR ENDING CRIMES OF VIOLENCE AGAINST CHILDREN AND ADULTS WITH DISABILITIES?

Editorial Commentary

This Report to the Nation identified almost all the major issues related to violence and disability with the exception of delineating specifically those responsible for ending crimes of violence against persons with disabilities. In the judgment of the Editor, the responsible agents are located at all levels of government to include agencies at the federal, state and local levels in addition to individuals, their families and their support systems.

At the start, it is important to caution all agents that under no circumstance should the victim of a crime of violence be blamed for his/her victimization.

The charts (See pages # 88 and 89) display the responsible agents at each level.

Federal Government

The first step in calling for a national priority and developing a national plan of action to end crimes of violence against children and adults with disabilities is for the President of the United States to issue an Executive Order that establishes a Presidential Commission on Ending Crimes of Violence Against Persons with Disabilities. At the same time, the U.S. Congress should be enacting a law that condemns crimes of violence against persons with disabilities, requires pertinent Federal agencies to coordinate their efforts to end the violence, and provides adequate funding for the mandate prescribed by the legislation. In addition, the U.S. Federal courts should be alerted to the alarming problem of crimes of violence against persons with disabilities and be prepared to respond to cases of persons with disabilities in an accessible and sensitive manner.

State Government

Each state should be required to adopt the Federal priority to end the violence against persons with disabilities by fully participating in the national mandate. Again, similar to the pattern requested at the Federal level, the state's pertinent agencies are requested to coordinate their efforts and resources. In addition to the Federal legislation that mandates a national program for ending the violence, state legislatures and the governors should enact further legislation that supplements the Federal law. Since the State Advocate for the Disabled usually has a direct line of communication with the Governor's office, he or she should become an ombudsperson in the development and implementation of the state-wide priority to end the violence.

Local Government

Since implementation of programs to provide direct services to children and adults with disabilities are at the local level, much of the program activity will occur in each municipality and community. Again, the pertinent agencies under the aegis of the Chief Administrator will be requested to interface with the State Advocate for the Disabled and coordinate their services in support of the program to end crimes of violence. These services should function in conjunction with the next levels of responsible agents – the local system of support services, the family and the individual.

FEDERAL GOVERNMENT

President

Attorney General and Secretaries of Health and Human Services, Education, HUD, Labor,
Transportation and Veterans Affairs

The U.S. Congress
Federal Judicial System

Responsibilities: (1) establish national priority for zero tolerance; (2) create Federal laws and legal sanctions; (3) fund mandates for major Federal initiatives in violence prevention and intervention; (4) develop national publicity campaign to raise awareness



STATE GOVERNMENT

Governor

State Advocate for the Disabled

Attorney General and Commissioners of Public Safety, Health, Mental Health, Social Services,
Education, Housing, Transportation, Veterans Affairs and Corrections

The Legislature
The Judiciary

Responsibilities: (1) establish state priority for zero tolerance in conjunction with Federal priority in violence prevention and intervention; (2) create State laws and legal sanctions that augment Federal laws; (3) fund mandates for major State initiatives in violence prevention and intervention; (4) implement federally funded mandates in violence prevention and intervention



LOCAL GOVERNMENT

Chief Administrator of Municipality (city or county)

Commissioners of public safety, health, mental health, social services, education, housing,
transportation, corrections and probation, veterans affairs, public information and community relations

The Legislature
The Judiciary

Responsibilities: (1) establish community priority for zero tolerance in conjunction with the Federal and State priorities in violence prevention and intervention; (2) create local laws and legal sanctions that augment Federal and State laws; (3) fund mandates for major local initiatives in violence prevention and intervention; (4) implement Federal, State and locally funded mandates for violence prevention and intervention; (5) provide accessible services and facilities for victims of crimes of violence



LOCAL SYSTEM OF SUPPORT SERVICES

Health Care Providers, Law Enforcement Personnel, Social Service Providers, Legal Advocates, Disability Advocates, Education Personnel, Assistive Technology Specialists, Special Education and/or Rehabilitation Counselors

Centers for Independent Living, local or regional offices of the Administration for Veterans Affairs, Professional and Parent Organizations devoted to advocacy for Children and Adults with Disabilities (such as United Cerebral Palsy Associations, The Arc, American Council of the Blind, Alexander Graham Bell Association for the Deaf, Developmental Disabilities Council, Spina Bifida Association, and Brain Injury Association), Office of Disability in the local schools and colleges and in local places of employment

Responsibilities: (1) implement community priority for zero tolerance for crimes of violence; (2) provide essential services, in a sensitive manner, to victims of violence with disabilities to include accessible transportation, housing, medical care, emergency personal assistants, available 24 hours per day, 7 days per week; (3) report victimization to law enforcement authorities as soon as a crime occurs



FAMILY

Parents, Siblings, Close relatives, Foster Parents, Close friends considered part of the family constellation

Responsibilities: (1) provide for the health, well-being, education, and safety of the child or adult with disabilities; (2) teach law-abiding and appropriate social and personal behaviors through bonding, role modeling, social learning, moral development and non-violent discipline; (3) establish a safe and protected living environment with attention to good lighting, safety devices, alarm systems, and accountability of an individual's location; (4) report victimization to law enforcement authorities as soon as a crime occurs; (5) cooperate with service providers to assist victimized family members; (6) never become the perpetrators of violence



INDIVIDUAL

Responsibilities: (1) play a significant role in the prevention of one's own exposure to potential for victimization; (2) become educated about violence and disability; (3) be "on guard" or wary about individuals who may become perpetrators of crimes of violence; (4) cooperate with authorities from law enforcement, social services and health care in the community program to prevent victimization or revictimization; (5) report crimes of violence against oneself or against others with guarantees of confidentiality and protection; (6) never become a perpetrator

Service Providers

These agents provide the necessary services in order for the child or adult with a disability to realize the full measure of independence and quality of life. Their responsibilities, therefore, extend beyond the day-to-day functions that assist in the realization of independence to include efforts to prevent victimization or revictimization. For example, when requested to provide a personal assistant, the agency should carefully screen and certify the service providers so that perpetrators are not assigned to the care of a child or adult. It is important to note that since the focus is on crimes of violence, law enforcement personnel play a significant role in the management of programs to prevent and to intervene in violence against persons with disabilities. In the event of victimization, under no circumstances should these crimes be treated as insignificant problems but rather clearly identified and reported to law enforcement authorities as crimes of violence. In providing intervention services, the victim should never be blamed for the victimization but should be treated in a sensitive manner and have accessibility to all necessary services.

Family

One of the unfortunate findings from the research and clinical literature and from anecdotal reports by persons with disabilities, is that perpetrators are frequently known by the victim because they are family members, relatives, close friends or acquaintances. A program to prevent crimes of violence against children and adults should include the need to educate and caution the family about violence and disability, identify ways to prevent victimization or revictimization, and inform the family members about the consequences of becoming a perpetrator and committing a criminal act. The family in consultation with the individual with disabilities should play a significant role in reporting crimes of violence.

One of the major responsibilities of the family is to provide the increased surveillance that is needed in order to protect the safety of the person with a disability.

In the event of victimization, the family should have information about available and accessible services that are necessary for the care of the victim.

Individual

It is recognized that there are some substantial differences between the needs of children with disabilities and adults with disabilities when one considers the topic of prevention and intervention against violence. Also, the type and severity of disability are important factors to consider in designing a plan of action to prevent and intervene in violence. For example, children with intellectual deficits should be informed as fully as possible about the topic, their role and future behavior. But it will be understood that these children will require greater surveillance as they interact with others in various life activities and locations. An adult with a spinal cord injury who is employed in a facility located in a high crime area will need to take very careful measures to be transported to and from the facility in a safe and protected manner.

Finally, as in any effort to end an undesirable consequence, the individual should assume a good measure of the responsibility within the parameters of one's ability to protect oneself from harm and the consequences of victimization.

APPENDICES

APPENDIX A:

CONFERENCE SPONSORS

Department of Physical Medicine and Rehabilitation, SUNY Upstate Medical University

Division of Violence Prevention, National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, US Department of Health and Human Services

Disability and Health Program, Division of Human Development and Disability, National Center for Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, US Department of Health and Human Services

Office for Victims of Crime, US Department of Justice

Office of Special Education Programs, Office of Special Education and Rehabilitation Services, US Department of Education

National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitation Services, US Department of Education

National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development, National Institutes of Health, US Department of Health and Human Services

Administration on Developmental Disabilities, Administration for Children and Families, US Department of Health and Human Services

Children's Bureau, Administration for Children and Families, US Department of Health and Human Services

Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services

National Council on Disability

Paralyzed Veterans of America

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APPENDIX D:
CONFERENCE PROGRAM OUTLINE

**“Preventing and Intervening in
Violence Against Children and Adults with Disabilities”**

May 6 and 7, 2002

**Holiday Inn Hotel and Suites, Historic District Alexandria
625 First Street, Alexandria, VA**

DAY ONE: May 6, 2002:

- 8 a.m. Registration
- 9:00 **PLENARY SESSION:** Opening remarks and conference organization: Dr. Dorothy K. Mage, Conference Coordinator. Welcoming comments and introductions by Dr. Robert J. Weber, MD, Chair PM&R, SUNY Upstate Medical University. All representatives of sponsoring agencies and organizations will be introduced and given an opportunity to welcome the participants.
- 9:30 **INVITED SPEAKER:** John Lutzker, Ph.D., Chief, Prevention Development and Evaluation Branch, Division of Violence Prevention, National Center for Injury Prevention and Control, CDC, “Violence Prevention: The CDC Role.”
- 10:00 **INVITED SPEAKER:** John W. Gillis, Director, Office for Victims of Crime, U.S. Department of Justice, “Victims of Crime with Disabilities: The Criminal Justice System and Victim Assistance Response”
- 10:30 Break
- 10:45 Conferees are assigned to one of four small discussion groups with 10 - 12 persons in each. Discussion Groups #IA and #IB will focus on violence against children with disabilities. Discussion Groups #IIA and #IIB will focus on adults with disabilities. Each discussion group will have a Chair, Resource Person or Persons), and a Recorder. Each discussion group will address the following three questions: 1. What is the scope and magnitude of the problem? (What are the current statistics about violence against persons with disabilities? How can we improve data collection and analysis? Recommended epidemiological studies?); 2. What are the ways people with disabilities and their families cope

with violence? (Victims' response to violence? Community support systems if available? Examples of ideal interventions for victims of violence?); 3. What steps should be taken to intervene and prevent such violence? (Recommendations for intervention and prevention; examples of field-tested approaches; and developing a research agenda.) Question #1 and #2 will be discussed on Day One and Questions #3 will be addressed on Day Two.

- 12 p.m. Luncheon break (working luncheon)
- 1:00 Discussion groups continues deliberations
- 2:00 Complete deliberations about Question #1. Begin discussion about Question #2.
- 3:30 Break
- 3:45 Continue discussion and complete deliberations for Question #2.
- 4:30 **PLENARY SESSION:** Conference reports on the progress and recommendations for Question #1 and #2. Group discussion and refinements of observations and recommendations.
- 5:15 Adjournment for the day.

DAY TWO: May 7, 2002:

- 8:30 **PLENARY SESSION:** Invited Speaker, Dr. Sylvia Walker, Director, CDSPS, Howard University, "Violence Against Persons with Disabilities: Who are the Most Vulnerable?"
- 9:00 **INVITED SPEAKER:** Stephanie Lee, Director, Office of Special Education Programs, U.S. Department of Education, "OSEP's Involvement in Issues Related to Violence Against Children with Disabilities"
- 9:15 **INVITED SPEAKER:** Steven J. Tingus, Director of the National Institute for Disability and Rehabilitation Research, U.S. Department of Education, "Preventing and Intervening in Violence Against Children and Adults with Disabilities: The Role of NIDRR."
- 9:30 Discussion groups meet to deliberate on Question #3.

- 10:15 Break
- 10:30 Discussion groups reconvene.
- 12 p.m. Luncheon break (working luncheon). Complete deliberations on Question #3.
- 1:00 **PLENARY SESSION:** Discussion groups present summaries of deliberations with findings and recommendations for Questions #3. Conferees participate in the review of findings and recommendations. Consensus on key findings and recommendations are the objectives of this session. Discussion of next steps.
- Collection of conference evaluation forms from participants.
- 3:00 Adjournment: Drs. Marge and Turk

CONFERENCE ASSIGNMENTS

For both Conference Days, May 6 and 7:

Small Discussion Group IA (Children)

Chair: Kelly Henderson, OSEP/OSERS/ED

Resource: Patricia Sullivan, Boys and Girls Town, USA; May Helen Witten, Centers for Disease Control and Prevention; Janey McMillen, University of North Carolina

Small Discussion Group IIA (Children)

Chair: Krista Biernath, Centers for Disease Control and Prevention

Resource: Joye Whatley, US Department of Justice; Rune Simeonsson, University of North Carolina at Chapel Hill; Melissa Brodowski, Childrens Bureau

Small Discussion Group IB (Adults)

Chair: Margaret Turk, SUNY Upstate Medical University

Resource: Larry Burt, Centers for Disease Control and Prevention; Rosemary Hughes, Baylor College of Medicine

Small Discussion Group IIB (Adults)

Chair: Ethel Briggs, National Council on Disability

Resource: Keri Lipperini, Paralyzed Veterans of America; Steve Tingus, NIDRR; Nancy Harvey Steorts

Moderator of Plenary Sessions for May 6 and 7:

Scott Brown, OSEP/OSERS/ED

APPENDIX E: CONFERENCE DEFINITIONS

An Overview and Definition of Violence

by Dorothy K. Marge, Ph.D.

Working Definition of Disability

by Michael Marge, Ed.D.

An Overview and Definition of Violence

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Introduction

Society has as one of its goals the establishment of social order in which basic human needs are met in a peaceful and regulated process. Social order “does not come naturally and without effort” (Campbell et al., 1969). Therefore, one of the major efforts of humankind is to learn to control violence and other antisocial behaviors that disrupt the peace. **Violence with its intense action and often-destructive results, perpetrated by one or more persons against one or more individuals, may be perceived as a form of social disorder.**

Van den Haag (1972) identified four political uses of violence: (1) to acquire power; (2) to exercise power; (3) to challenge authority; and (4) to enforce authority. Under the first category, acquiring power, he referred to acts of terrorism and revolution.

In the second category, the exercise of power, he referred to those circumstances when a person has already “acquired power and uses excessive violence to exercise power,” such as the dictatorships of Stalin and Hitler. The third category (challenging authority) would include riots against a repressive regime and race riots in America during the 1960’s.

Finally, the fourth category (to enforce authority) included law enforcement activities and war. These are violent behaviors that are accepted and approved by society under certain circumstances. Such circumstances permit violence by governing authority within the parameters of that which is considered “legally permissible.”

The United States has moved from less complex social controls that were deeply embedded in the traditional institutions, such as family and church, to more complex social controls that are instituted through impersonal, legal, highly formalized and structured governmental organizations, such as law enforcement agencies.

Historically, as one examines the social and cultural factors that have molded the American character to tolerate and, in fact, perpetuate expressions of violence, the following is revealed (Marge, 1996):

1. It is clear that our Nation has had a long and intense experience with violence, both state approved and illegitimate, beginning in the colonial period and extending to the present day with violence experienced in all phases of daily living—e.g. home, school, church, community and work.
2. This history has established a milieu in which violence, legitimate and illegitimate, can thrive and, in fact, is openly encouraged in certain circumstances. The legitimate circumstances include state-sanctioned violence, such as war. The illegitimate circumstances refer to vigilantism, gang wars, organized crime and excessive force by the police.
3. There are certain key elements that increase the potential for violence in America.

- (a) The first of these is the media, in all of its forms, with its obsession on reporting and describing, in excruciating detail, all types and forms of violence to children and adults (Miedzian, 1991). In addition, the motion picture industry has produced films that may expose children and adults to violence and encourage the development of desensitization and greater tolerance toward acts of violence and deprivation without identifying the consequences of perpetrating violence. Toys and games, particularly certain video games with their game protocols, encourage violence and the destruction without negative consequences. Furthermore, contact sports have been viewed as exhibitions of violence.
- (b) The second element is the illegal use of drugs and irresponsible use of alcohol, which have been shown to increase the prospect of crime and violence.
- (c) A third element is easy access to weapons. As we have learned from experiences at airports post September 11 (2001), many objects in addition to firearms may be considered as weapons that could result in fatalities or serious injuries.
- (d) The fourth element is the longevity, proliferation and lethality of gangs in major cities throughout America. Compounding the problem of gang behavior has been the influence of the drug trade in increasing the growth of gangs.
- (e) And, finally, the fifth element is the impact of the economy on the increasing potential for violence, both on the individual and group basis.

The family's influence on the development of violence

The family is conceived in its *broadest* sense in terms of type, constellation and refers to a group of individuals united by a common affiliation. The family is responsible for a number of significant activities. These include, but are not limited to, bonding, social learning, moral development, and discipline. Monahan (1981) stated that the family environment is critical in its role of supporting or discouraging violent behavior.

Bonding

The family plays an essential role in the development of a strong, loving interpersonal relationship between the child and the primary "caregiver or parent". When this relationship is disrupted, it may result in behaviors which, together with other factors, later leads to act of violence (Farrington, 1989). Rutter (1972) stated that "if the bond never forms, consequences can be very severe and may lead to 'affectionless psychopathy' which begins with an initial phase of clinging, dependent behavior, followed by attention-seeking, uninhibited, indiscriminate friendliness, and finally a personality characterized by lack of guilt, an inability to keep rules, and an inability to form lasting relationships."

Social learning

It is within the context of the family that learning first takes place. Eron (1990) has indicated that aggressive or violent behaviors are learned responses to frustration and may become instruments for achieving goals. The parental models, especially, facilitate the aggressive or violent behavior.

Moral development

According to Kohlberg (1978), the development of moral reasoning progresses through three levels, with two stages at each level. At the lower stages of moral reasoning are concreteness and egocentricity. At the higher stages are abstract concepts of justice and rights and are more social in orientation. It is postulated that delinquent behavior is related to the delay in the development of moral reasoning. Nelson et al. (1990) indicated that the strength of the relationship between moral reasoning and delinquent behavior must take into account a number of other variables, such as cognitive development and within group differences. Wilson and Herrnstein (1985) proposed that persons who engage in criminal behavior are deficient on three factors arising from family experience: development of attachment or bonding, the development of understanding of consequences over time, and the development of conscience.

Discipline

Caregivers in families use discipline in response to certain behaviors in children. A number of studies indicated that severe discipline that uses physical punishment for broken rules increases aggressive behavior in children. It also may provide a model of aggressive behavior that children may imitate. When parental rejection is coupled with severe punishment, the child has slow conscience development and exhibits aggression (Eron et al, 1974; Faretra, 1981; Patterson, 1979). Reiss and Roth (1993) found that there is a relationship between the victim of physical abuse and neglect as a child and later violent behavior.

Children and adults with disabilities as victims of violence

Although much has been written and studied about children and adults who have been victims of violence, there is a population which has been hidden from the scrutiny of researchers and service providers: children and adults with disabilities. For some reason, perhaps lack of awareness, the general public has ignored the impact of violence on persons with disabilities. Baladerian (2002) reported that children with disabilities are not perceived as possibly being victims of child abuse, neglect and maltreatment. Although there have been some recent studies of violence against women with disabilities, particularly domestic violence, for the most part the public perceives that persons with disabilities do not have partners or sex lives. And, we should not overlook that men with disabilities are also victims of violence. In a “macho” culture where men are reluctant to admit to victimization, it is still important to identify problems that men with disabilities face. Lee et al. (2002) expressed the need to study the impact of violence against persons of color but the study should be expanded to include violence against persons of color who have disabilities.

Acts of violence, both intentional and nonintentional, criminal and noncriminal may occur to persons with or without disabilities regardless of age, gender, race, sexual orientation, religion or other characteristics. Violence is found in environments that include the home, school, church, community and work. Recent reports of violent behavior have been identified in some, heretofore, unexpected environments. For example, incidents of road rage, air rage, parking lot rage, and parental rage at children’s athletic events have escalated in violence to the point of fatal injuries or death to victims of these attacks. Sexual abuse of children, for example, has occurred in day care centers by caregivers, in schools by teachers or other authority figures, in churches/other religious facilities by priests or other religious personnel, in camps by counselors, in health care settings by health care

providers as well as in other institutions where the safety and care for vulnerable and dependent persons has been entrusted and would never be questioned. School safety, aside from the problems of pedophilia or paraphilia, is now an environment for contemporary concern where children may seek “revenge” by using deadly force (bombs and guns) and killing their tormentors, those whom they perceived as having teased, bullied, humiliated, excluded and dehumanized them. For these child perpetrators, access to weapons to commit these and other weapon-related acts is easily available.

Terrorism is defined by the Department of Defense as “the calculated use of violence or the threat of violence to inculcate fear; intended to coerce or to intimidate governments or societies in the pursuit of goals that are generally political, religious, or ideological” (Terrorism Research Center, 2002). Once considered a dreaded experience that occurs to persons in other countries, now it has come to our shores, along with concerns about anthrax and other biological and chemical agents that could be used as weapons against the American population. Post traumatic stress disorder is no longer a condition that is confined to terrorism or government sanctioned violence (war). It is now recognized as a possible consequence of witnessing or experiencing “non-war” related acts of violence.

Hate crimes and their violent results are currently the subject of interest for many researchers. Persons who do not conform to the “organizational perception” of acceptability by hate groups may be targeted for violence (Dees, 1996).

The technological advances in the United States has a “downside” with the use of the computers for cyberstalking and harassment; where perpetrators, using chat rooms, could bait and lure persons to environments where acts of violence could be committed, and where the growth of the pornography industry provides easy access of pedophiles and paraphiles to child pornography and other forms of degradation

We must realize that persons with disabilities who experience violence are not the only victims. There are “secondary victims” as well, those who are parents, children family members or caregivers of the victims. They may experience stress, anxiety and fear for the safety and life of the victims as well as their own.

If we are to really address the problem of violence in America, it will require a one-on-one change in interpersonal behavior where we seek peaceful conflict resolution to the current and future problems we face in a complex and global society. The methodology of no-violent conflict resolution in addition to respect for human dignity must be given the highest priority in our daily living (Marge, 1996).

A recently released study commissioned by the Pew Charitable Trusts entitled “Aggravating Circumstances: A Status Report on Rudeness in America” concluded that “79 percent of those surveyed say that lack of respect and courtesy are a serious national problem and 61% believe the problem is getting worse.”

There is a need for national leadership to encourage the development of civility, courtesy and respect for one another as citizens in America, regardless of our differences. It is interesting to note that recently, the United States Naval Academy in Annapolis, Maryland with its “unfashionable advocacy of duty, patriotism and honor is going against the strongest currents of our culture by instituting formal training in etiquette for its midshipmen” (The Capitol, 2002). If civility, courtesy and respect for others cannot be developed within the context of the family, then let others step forward.

For the purpose of this Conference, **violence is defined as any harmful act against persons with disabilities that will result in physical and/or mental injury or death.**

These acts may occur in any situation in which persons with disabilities are victimized by family members, friends, caregivers, teachers, religious figures, service providers and strangers. The victimization may take the form of physical neglect, emotional neglect, physical abuse, emotional abuse, and sexual abuse leading to physical injury and/or death. Victimization of persons with disabilities is of particular concern because of the extensive reports of vulnerability, lack of public awareness of the problem, concealment and acceptance of abuse and violent acts, as well as the need for protection, safety and accessible services that are effective and sensitive to the needs of those who have become victims.

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Working Definition of Disability

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Introduction

The search for a definition of disability that is politically correct, meaningful and utilitarian has been difficult and challenging. In an ideal world, the differences in individuals should be perceived as matter of fact and a reflection of nature. Some would prefer that the differences are accepted even more positively as evidence of the uniqueness of each individual. The insightful student of history will recognize, however, that American society's perception about disability is in a period of transition from (a) one that assesses the differences as deficits, deviations from the norm, and demeaning to (b) the current one that protects the rights of each individual from discrimination, provides public-sponsored programs to accommodate the needs of persons with disabilities, and raises the sensitivity and awareness about the importance of accepting differences as an expected norm. This author predicts that before the end of this century the term disability will no longer be culturally or socially appropriate (as contrasted with politically acceptable) and individuals will be referenced by their name without any further qualifications—a world that accepts and appreciates the differences in others and interacts with an individual's strengths and not their weaknesses. This will be a world that provides the essential services and programs to assist each individual to realize the greatest degree of independence and well being.

During the past four decades a number of important developments have resulted in transforming the definition of disability from one that focused on the health condition of the individual to the current definitions that address the interactions between the individual and the environment. Some of these important developments included the Rehabilitation Act and its subsequent amendments, the American with Disabilities Act (ADA), the Individuals with Disabilities Education Act, the World Health Organization's International Classification of Functioning, Disability and Health (ICF), the growth of politically active advocacy groups (such as the Consortium for Citizens with Disabilities), and the emergence of nationally recognized leaders with disabilities or with family members with disabilities.

A survey of Federal statutory definitions of disability conducted on behalf of the National Institute on Disability and Rehabilitation Research (Domzal, 1995) reveals that there are 50 acts and programs with their own definition of disability. It underscores one of the purposes of definitionst— providing a rubric for the distribution of support or services. For example, the Social Security Administration's definition of disability states (Social Security Administration, 2002), "To be considered disabled under either the Disability Insurance or the SSI program, a person must be "unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that has lasted or is expected to last 12 months or to result in death. An individual's physical or mental impairment(s) must be of such severity that he is not only unable to do his previous work but cannot, considering his age, education and work experience, engage in any kind of substantial gainful activity which exists

in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.”

The ADA’s Statutory Definition (The U.S. Equal Employment Opportunity Commission, 2001) is as follows – “With respect to an individual, the term “disability” means (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment. A person must meet the requirements of at least one of these three criteria to be an individual with a disability under the Act. The first part of the definition covers persons who actually have physical or mental impairments that substantially limit one or more major life activities. The focus under the first part is on the individual, to determine if (s)he has a substantially limiting impairment. To fall under the first part of the definition, a person must establish three elements: (1) that (s)he has a physical or mental impairment (2) that substantially limits (3) one or more major life activities. The second and third parts of the definition cover persons who may not have an impairment that substantially limits a major life activity but who have a history of, or have been misclassified as having, such a substantially limiting impairment, or who are perceived as having such a substantially limiting impairment. The focus under the second and third parts is on the reactions of other persons to a history of an impairment or to a perceived impairment. A history or perception of an impairment that substantially limits a major life activity is a “disability.” These parts of the definition reflect a recognition by Congress that stereotyped assumptions about what constitutes a disability and unfounded concerns about the limitations of individuals with disabilities form major discriminatory barriers, not only to those persons presently disabled, but also to those persons either previously disabled, misclassified as previously disabled, or mistakenly perceived to be disabled. To combat the effects of these prevalent misperceptions, the definition of an individual with a disability precludes discrimination against persons who are treated as if they have a substantially limiting impairment, even if in fact they have no such current incapacity.”

In comparison with the definition of the ADA, the SSA definition is very strict and excludes many individuals who either perceive themselves or are perceived by others to be disabled.

Prevalence of Disability

Based on studies of the U.S. population in 1994 - 95, it is estimated that there are 54 million persons in the United States or 20 percent of the population with disabilities (McNeil, 1997). If one extrapolates these statistics to the 2000 census (estimated 275 million people), there may be as many as 55 million persons living with a disability.

The research and clinical literature on the health and safety needs of persons with disabilities is extensive (see Volumes I and II in the Pre-conference packet). It points out that although all individuals are at some degree of risk for violence and victimization by perpetrators of violence, people with disabilities in general may be at greater risk than others.

Conceptual Considerations

Since the focus of this Conference is on people with disabilities, it is necessary to examine the specific problems and issues that relate to the prevention of violence and the effective interventions required in the event of a victimization. At this point, several concepts should be introduced and discussed. They are:

1. **Vulnerability:** refers to the probability of becoming a victim of violence. Degree of risk is oftentimes used synonymously with vulnerability. The terms have somewhat different meanings. Degree of risk refers to a measure of potential exposure to victimization whereas vulnerability implies that an individual has a high degree of risk for victimization.

Many individuals with and without disabling conditions have the capability to avoid dangerous exposures to violence (relatively low degree of risk for exposure and victimization) and if confronted with a potentially violent situation have the ability to escape or protect themselves from harm. According to the circumstance, despite all the capabilities and coping behavior, it is possible that an individual may be unsuccessful and realize serious harm or death. Persons with disabilities who may have limitations in mental or physical function, such as vision, hearing, talking, walking and running, may be at greater risk for serious harm or death. For example, a person who is blind in an isolated situation with a dangerous perpetrator is seriously compromised in terms of escape or personal protection. An individual who relies on a wheelchair and is in an isolated situation is compromised if confronted with a dangerous perpetrator who demands money. A colleague who uses a wheelchair and lives on the West Side in Manhattan informed me that he needs to know the cost of the “fix” for the day in order to carry enough cash to deter the potential attacks of drug users. A thief may confront him on the street with a demand for money even in the presence of others. Some thieves have threatened to push his wheelchair into the path of an auto or push him out of his wheelchair on to the street if they did not receive money.

2. **Accommodations:** refers to the programs and services required to reduce the vulnerability and the degree of risk for becoming a victim of violence. The activities include the following: (a) provision of assistive technology to increase the capacity necessary for independent behavior, (b) provision of training on how to prevent victimization, (c) provision of a personal assistant or companion for purposes of protection and safety, (d) independent and objective monitorship of children with disabilities by a case manager or oversight evaluator with public authority (to prevent child abuse, neglect, maltreatment, and exposure to violence), (e) provision of attentive and effective law enforcement for safety in places where people with disabilities reside, work and recreate, (f) effective, sensitive, and prompt law enforcement and health services for crisis intervention when a person with a disability is victimized, (g) effective training of victims of crime to prevent any future victimization, and (h) active community-based programs to reduce and prevent crime through law-enforcement, the courts and citizen-action groups.
3. **Situations that may promote violence:** refers to the physical circumstances, the expected behaviors of individuals within the physical circumstances, and interaction with the child or adult with disabilities. The following situations have been identified where people with disabilities have become victims of violence:

- a. Children and adults in institutions for the disabled
- b. Infants and children at home with caregivers and parents
- c. Seriously debilitated adults with personal assistants
- d. The elderly with disabilities in nursing homes
- e. Children and adults on the streets in inner cities

Working Definition

For purposes of this Conference, therefore, a working definition of disability is: physical and/or mental limitations that (a) reduce their capacity for self-protection and prevention and thereby (b) increase their vulnerability for victimization by violence, especially if they are placed in certain potentially violent situations. The definition implies that there is need for special accommodations for the limitations of persons so that the individual with a disability may realize an equally substantial reduction in degree of risk and therefore, reduced vulnerability. Also, the definition implies that certain situations need to be addressed as potentially dangerous for individuals with limitations.

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APPENDIX F:
COMMISSIONED PAPERS AND CONTRIBUTIVE
BIBLIOGRAPHY

**Violence against Children with Disabilities: Prevention,
Public Policy, and Research Implications**

by Patricia M. Sullivan, Ph.D.

**Interventional Approaches for Children with Disabilities who
are Victims of Violence**

by Donald C. Bross, J.D., Ph.D.

Violence Against Women with Disabilities

by Margaret A. Nosek, Ph.D.; Rosemary B. Hughes, Ph.D.;
Heather B. Taylor, Ph.D.; Carol Howland

**Intervention Approaches for Adults with Disabilities Who
Become Victims of Violence**

by Nora J. Baladerian, Ph.D.

Selected References – Children and Youth

by Janey S. McMillen, Ph.D. and Rune J. Simeonsson, Ph.D.

VIOLENCE AGAINST CHILDREN WITH DISABILITIES: PREVENTION, PUBLIC POLICY, AND RESEARCH IMPLICATIONS

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Parts of this paper were originally commissioned by the Committee on Law and Justice of the National Research Council in response to a Congressional mandate in the Crime Victims with Disabilities Awareness Act of 1998 and disseminated at the Workshop on Crime Victims with Developmental Disabilities at the University of California, Irvine, October 27, 1999.

Violence Against Children with Disabilities: Prevention and Public Policy Implications

“As long as little children suffer, there is no true joy in the world” . Isadora Duncan

Introduction

This paper will address what is known about the prevalence and nature of violence committed against children with disabilities, discuss current public policy issues regarding victimized children with disabilities, and delineate additional research that needs to be undertaken in the field of violence and disabilities. To consider the extent of violence and abuse against children with disabilities, it first focuses on historical perspectives on the problem from early records to the present. Secondly, current prevalence estimates of childhood disability in the U.S. are presented along with a consideration of varying definitions of disability status in childhood including those used in education, health care, and mental health residential facilities. Disability related cultural issues are also discussed, particularly as they relate to existing definitional models of disability. A summary of the existing data on violence and abuse against children with disabilities is presented including conventional violent crimes, specialized crimes, and noncriminalized violent acts. Particular emphasis is placed upon the abuse and neglect of children with disabilities including disability related risk factors, co-occurring factors in the maltreatment of children with disabilities, and child maltreatment that does not attain the level of criminality. Epidemiological data on the prevalence and characteristics of abuse and neglect of children with developmental disabilities are presented (Sullivan & Knutson, 1998a; Sullivan & Knutson, 2000a). Condoned physical interventions with children with disabilities, which can escalate to abuse, institutional abuse, and disabilities that result from child maltreatment, are also included.

The articles reviewed were identified through computerized searches (e.g., PsychLit, CINAHL, Medline, and CAN), annotated bibliographies, journals that typically publish articles on violence and abuse, and personal communications with researchers. Existing databases on crime statistics were accessed via the Internet and by telephone contact with individuals responsible for data collection and analyses. A computerized search of four databases was conducted to identify

articles addressing disabled children as victims of violence: one psychological database (Psychlit), two medical databases (Medline and CINAHLs), and the Child Abuse and Neglect research database (National Clearinghouse on Child Abuse and Neglect Information). The search of the first three databases identified 2,640 possible citations (Psychlit 812, Medline 1,323, and CINAHLs 505) when queried for children as victims of crime and violence. These citations were cross-queried with general disability status and reviewed for content. Only six (6) articles were identified that addressed disabled children as victims of crime. The search of the Child Abuse and Neglect database identified 676 articles, chapters, and discretionary grants when queried for children with disabilities. All articles were reviewed and fifteen citations were case studies, 56 research studies with original data, and the remaining 605 were literature reviews, program descriptions, and contained no original data. Finally, the review focuses on barriers to obtaining information addressing violence and abuse of children with disabilities and addresses future needs in the field, including a recommended research agenda.

Historical Perspectives

“At the bottom of the heart of every human being from earliest infancy until the tomb, there is something that goes on indomitably expecting, in the teeth of all experience of crimes committed, suffered, and witnessed, that good and not evil will be done to him or her. It is this above all that is sacred in every human being”. Simone Weil, 1943

Children and youth with disabilities have been victims of crime throughout recorded history. The decision to nurture, abandon or murder a child has been based on a cultural-utilitarian perception of the needs of the social group and, accordingly, the fate of children, particularly children with disabilities, has historically been outside their own control (Kolstoe & Frey, 1965; Safford & Safford, 1996). For the purposes of this review, which is by no means exhaustive, condoned societal violence and abuse toward children with disabilities are briefly summarized within five broad historical eras: Infanticide and/or Abandonment in Ancient and Classical Civilizations; Ridicule/Amusement/Oblation in the Middle Ages; Asylum/Superstition/Execution in the Renaissance and Reformation; Institutions and Abuses during the Industrial Revolution; and the 20th Century. However, it must be emphasized that across these eras, a range of treatment, from acceptance and care to rejection, abandonment and murder of individuals with disabilities can be found (Boswell, 1988). Archeological evidence has revealed relatively long life, group inclusion, and even attempts at surgical correction of individuals with physical disabilities in ancient civilizations (Lowenfeld, 1975; Scheerenberger, 1983). Unfortunately, the 2,500-year historical sample is not a linear progression toward the elimination of violent and abusive behavior directed at children with disabilities.

Infanticide/Abandonment (Ancient and Classical Civilizations: 500 BC – 500 AD)

Among the early Greeks, especially the Spartans who valued a population with militaristic abilities, all infants were brought before a panel of elders who determined if they were fit for military training. Those with obvious physical disabilities were transported out of the city and abandoned in the surrounding hills. In Athens, the fate of a newborn was determined by the father who decided if the child would be allowed to live or disposed of in clay vessels left by the roadside (Boswell, 1988). Plato's *Republic* (1928, translation) advocated both eugenics and

infanticide: "...the offspring of the inferior, or the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be" (p. 413). Aristotle's *Politics* (1957) advocated a law that "no deformed child shall live" (p. 315). The Roman Law of the Twelve Tables declared children to be the property of their father's who, during the first eight days of life, made the decision to keep the infant, sell it into slavery, or set it adrift in the Tiber in a basket specifically designed for that purpose (Boswell, 1988). Consistent with the Roman legend of the abandoned infant twins Romulus and Remus, it was believed that abandoned infants would be found and reared by some one else (Boswell, 1988). This did, indeed, occur in some circumstances but, in others, abandoned children were maimed by state supplied wet nurses in order to enhance their appeal as beggars (Safford & Safford, 1996).

Ridicule/Amusement/Oblation (The Middle Ages: 501 - 1460)

During the Middle Ages, children with disabilities were sometimes provided with shelter and sanctuary within the manors of wealthy nobles. In return, they were to provide amusement to all who resided within the manor and were kept as "fools" or court jesters. Exploitation through exhibition was commonplace. Within the layers of feudal society, ridicule of less fortunate persons, including children and adults with disabilities, served to legitimize the class inequalities within the feudal system (Heward & Olansky, 1992). In *The Confessions of St. Augustine*, inherent propensities for evil were attributed to children, particularly those who were the product of "sin", which could be evidenced by a birth defect or disability and were considered to represent punishment for parental sin or the workings of Satan (Safford & Safford, 1996). The abandonment of children with disabilities was replaced by oblation, a practice in which parents offered their children to others to raise, primarily in monasteries and convents, and could not be withdrawn under threat of excommunication (Safford & Safford, 1996). Oblation was a major source of recruitment for monasteries and convents and the majority of the children had some type of disability (Boswell, 1988). Boswell (1988) cites data indicating that some 85% of monks in an English monastery were oblates and quotations from St. Jerome and an 11th century church official, respectively, indicating that "parents dedicate to virginity those daughters who are deformed or defective in some way" (p. 240) and "parents commit to monasteries any deformed, dull or unpromising children they have" (p. 298).

Superstition/Extermination (Renaissance and Reformation: 1461- 1707)

During this era, superstitions and false beliefs surrounded children with disabilities. Disabilities were considered to be the "mark of the devil" and could include a birthmark, cleft lip, cleft palate, polydactyly, clubfoot or a host of other genetic anomalies. Any disabilities that did not disappear after primitive treatments and religious rites were assumed to be the work of the devil or witchcraft. Children with cognitive delay, seizure disorders, or any bizarre behavioral manifestations were subject to trial and execution and unknown numbers of children and adults with disabilities were slain during the religious inquisition occurring within the Renaissance and Reformation (Safford & Safford, 1996). Both Luther and Calvin thought that mentally retarded children were possessed by the devil and were, accordingly, objects of revulsion (Boswell, 1988). This historical period also marked the appearance of asylums for children and adults with disabilities although the motives for establishing them are not clear, with religious reasons most often hypothesized (Safford & Safford, 1996). These asylums also provided shelter to other segments of society including the

poor, mentally ill, unmarried pregnant women, and wayfarers. Unfortunately, sanitary conditions were deplorable and, particularly during the Bubonic Plague epidemic, many perished in the very asylums designed to give them safety and sanctuary from societal violence and abuses (Shahar, 1990).

Institutions and Abuses (Age of Enlightenment and The Industrial Revolution: 1708 – 1899)

At the dawn of the Age of Enlightenment conditions worsened in the asylums and the poorhouses to such an extent that the 18th century has been called “the beggars century” (French, 1932). The asylums and poorhouses became so overcrowded that repressive measures and militaristic regimentation were implemented to control the residents. During this time, the transformation from an agrarian to an industrial society occurred and families were displaced from farms to cities. Child labor was extremely common because it was a cheap source of labor and children as young as four worked in the factories (Safford & Safford, 1996). Felt (1971) noted the common attitude toward child labor at the time was “if there is a job in a factory that could be done by a five-year-old, one should be hired to do it” (p. 41). Factory workers were also required to employ one “idiot child” from an asylum for every twenty-poorhouse inmates. Workdays were typically 12 to 15 hours in length. The children were often chained to their workstations and physical abuse by the overseer was common to ensure that the children kept working. More than half of the children employed, in factories and elsewhere, died, particularly from tuberculosis, or became disabled as a result of the harsh treatment and working conditions (Safford & Safford, 1996).

20th Century and Beyond

Violence, abuse, cruelty and ignorance toward children with disabilities survived into the 20th century and continue to this day. The century began with the Eugenics Movement, which sought to eliminate “defective” individuals, a hallmark of which was the institutionalization and sterilization of children and adults with disabilities (Allen, 1999; Reilly, 1992; Selden, 1999). The most infamous examples of violence and abuse occurred in Nazi Germany when some 275,000 adults and children with disabilities were murdered systematically between 1939 and 1944 and an additional 400,000 were forced to be sterilized (Sobsey, 1994). In the United States, the sterilization of individuals with disabilities has been permitted by law as well as the euthanasia of infants with severe disabilities (Sobsey, 1994). In Greece, Russia and Eastern European nations, infants with disabilities are abandoned to institutions with systemic neglect and abuses including tying children to their beds throughout the day with no stimulation. The notorious 1989 Glen Ridge, New Jersey case of the rape of a girl with developmental disabilities by privileged and popular teenage males and the subsequent silence of most of the community is a more recent example of the criminal victimization of individuals with disabilities and societal reaction to it (Lefkowitz, 1997). At the close of the century, child maltreatment was declared a public health epidemic and a national call to action to eliminate it was issued (Chadwick, 1999). Systematic data on children with disabilities as victims of crime and child maltreatment were neither recorded nor maintained in government databases. Children with disabilities were found to be 3.44 times more likely to be a victim of some type of child maltreatment than nondisabled peers (Sullivan & Knutson, 1997). The answer to the call to action will occur in the 21st century. Research addressing violence and abuse directed at children with disabilities and the resulting public policy that drives research and practice will, hopefully, be the cornerstones of that answer.

Prevalence and Definitional Issues

"I really cannot, and never will, presume to 'educate' the public...that being disabled never means 'disabled in toto', but to recognize that 'disabled' also means 'enabled', and that I would like to see the public become more aware of".
Antoinette De Wit (1989)

Disability is a heterogeneous categorization, and various strategies for operationally defining disability status must be considered. These range from medical models of physical deficits to inclusion models of challenges and cultural differences. These operational definitions adopted by researchers, medical providers, educators, the federal government and people with disabilities have determined the data that are available at the present time regarding violence and abuse of children with disabilities, including the prevalence and incidence estimates that can be made. Many groups collect data on disability status among children. There are currently no mandates or resources for a comprehensive demographic study of disability status among children. Consequently, existing "data" are best described as estimates, projections and best guesses. The results of these estimates vary as a function of the agency in the social ecology that is collecting the data, how disability status is defined, severity of the disability, age range employed, and the need for disability related services.

Some 5.3 million children and youth with disabilities received special education services in the U.S. during the 1993-94 school year (Kaye, 1997). These 5.3 million children represented some 12.2% of all children enrolled in public schools and included 4.7 million children between the ages of 6 and 21 attending primary and secondary schools and 582,000 children aged 5 and younger attending preschool and early intervention programs. Children with behavioral/emotional problems, mental retardation, and learning disabilities taken together accounted for 71% of children receiving special education services and speech and language impairments comprised an additional one-fifth of these children with disabilities.

Approximately 2% of the children and youth with disabilities in the U.S. in 1992 lived in institutions, including nursing homes, schools for the blind, deaf, and physically disabled, institutions for the mentally retarded, and facilities for the mentally ill (U.S. Census Bureau, 1992). Children and youth with emotional and behavioral disabilities requiring residential treatment represent a burgeoning population in the U. S. Current estimates (U. S. Department of Health and Human Services, 2000) suggest there are some 227,200 children and youth in residential treatment centers (RTCs) in the U.S. in a given year. An additional 588,000 children and youth are in out-of-home care, including foster care and kinship care in the U.S. (U.S. Department of Health and Human Services, 2001). The number of children and youth receiving inpatient psychiatric treatment for a mental health problem is unavailable yet this group consumes almost half of child mental health resources. Many of these children have unrecognized and unidentified disabilities and are placed in out-of-home care pursuant to court orders due to child abuse and neglect. Approximately one in three children with disabilities is a victim of some form of maltreatment primarily by parents and immediate family members (Sullivan & Knutson, 2000). Medical findings requiring health care have been identified in 60% of children placed in foster care and children placed in care due to neglect have the greatest number of medical findings (Takayama, Wolfe, & Coulter, 1998). More than half of the children placed in foster care are victims of neglect (Kluger, Fein, & Maluccio, 1988). Neglected children placed in foster

care remain twice as long as children who are physically or sexually abused (Jackson, 1984). Victims of neglect placed in foster care receive fewer mental health services than children placed for physical or sexual abuse (Garland, Landsverk, Hough, & Ellis-MacLeod, 1996).

Many individuals with disabilities consider themselves to be members of a minority group (Nagler, 1993). As such, they are a diverse group of individuals who taken together comprise the largest minority group in the U.S. with, according to 1990 U.S. Census data, 49 million Americans with disabilities compared to 29.3 million African Americans, 22.3 million Hispanics, 7.0 million Asian/Pacific Islanders, and approximately 1.8 million Native Americans/Eskimos/Aleuts. Deaf and hard of hearing people, who represent around 1% of the disabled population, consider themselves to be a distinct subculture (Dolnick, 1993). Membership in this Deaf subculture is self-determined as 90% have parents with normal hearing. Acceptance of the Deaf subculture is indicated by the words used to describe the hearing impairment, i.e., Deaf or hard of hearing referring to the subculture, and hearing impaired as identifying with the broader culture embracing Americans with a great deal of diversity. The Deaf community has its own language (i.e., American Sign Language), folkways, and a sense of 'peoplehood'. However, other individuals with disabilities such as mental retardation, visual impairment, learning disabilities, health and orthopedic disabilities do not maintain that they have a common culture, language, mores, folkways, laws, and a sense of 'peoplehood'. Thus, the notion of culture is disability specific.

The biomedical approach within Western science and clinical medicine views disability as the diagnosis of some kind of illness or deficit, primarily motoric or cognitive in nature (Wang, 1992). This is offensive to many people with disabilities because of the implication that the impairment is an inherent trait within the individual and, in essence, pathologizes the person with the disability. Disability rights activists maintain that functional limitations, such as the inability to walk, hear, learn, or lift, are characteristics of the person's existence but say nothing about his or her essential character or personhood. There are some people who simply do not want to be categorized in any manner (medical, educational, legal, or entitlement) as having a disability. In sensitivity to these issues, the World Health Organization defines health as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (Wang, 1992). There are no prevalence data on the number of individuals who do not want to be counted as "disabled" and the particular "disability" groups they would comprise if counted. These cultural barriers compound the current prevalence and definitional difficulties and demonstrate the need for a philosophy and climate of inclusion of various disabled groups and parents of children with disabilities in determining definitional standards to be used in gathering prevalence data.

Disparate definitions of childhood disability present a formidable barrier and challenge to the determination of the nature and extent of violence and abuse committed against infants, toddlers, children and youth with disabilities. There is an acute need for consistently applied definitions of children with disabilities, which are operational and acceptable to the various disability communities and to parents of children with disabilities. A comprehensive demographic study of the disability status of children in the U.S. needs to be undertaken for the purpose of identifying and defining the nature and access problems to disability data faced by statisticians and researchers in the criminal justice, injury prevention, and child abuse and neglect fields.

Crime Statistics Systems and Children with Disabilities

“Society chooses to disregard the mistreatment of children, judging it to be altogether normal because it is so commonplace”. Alice Miller, 1986

Children with disabilities are essentially not included in crime statistics systems in the U.S. Thus, there is a lack of baserate data on child victims with and without disabilities ranging in age from birth to 21 for all types of violence for which victim data are typically gathered. The major crime statistics, health statistics, and child abuse and neglect statistics systems were accessed to determine what information, if any, is collected on victim and disability status. These included: Uniform Crime Reports, National Crime Surveys, National Center for Injury Prevention and Control, and the National Incidence Studies conducted on child abuse and neglect. Each source was reviewed for definition of disability, the age range of the child on whom information was collected, and the type of information collected.

The Uniform Crime Reports (UCR), maintained by the Federal Bureau of Investigation (FBI) since 1929, collect data from law enforcement agencies throughout the U.S. on homicides, forcible rape, robbery, aggravated assault, burglary, larceny-theft, motor vehicle theft, and arson. The Violent Crime and Law Enforcement Act of 1994 amended the Hate Crime Statistics Act to include crimes motivated by a bias against persons with disabilities. To comply with this federal mandate, the FBI began collecting data on crimes motivated by a disability bias on January 1, 1997. The FBI Uniform Crime Report Handbook defines a disability bias as “a preformed negative opinion of or attitude toward a group of persons based on their physical or mental impairments/challenges, whether such disability is temporary or permanent, congenital, or acquired by heredity, accident, injury, advanced age, or illness” (Federal Bureau of Investigation, 2000). Disability bias crimes are divided into two categories, physical and mental, which are not specifically defined in the Uniform Crime Report Handbook. In 2000, a total of 8,152 hate bias crimes were reported, thirty-six (36) of which were coded as motivated by the victim having a disability. No other data were available from the UCR on the types of disabilities of the victim or their ages. These statistics are voluntarily provided by law enforcement agencies across the nation. The labeling of a crime as a hate bias crime and the type of disability is left to the discretion of the individual law enforcement officer completing the crime report. No validity or reliability data are obtained on the disability status of the victim. These are the only statistics gathered by the FBI that include disability status of the victim.

The Bureau of Justice Statistics (BJS) in the U. S. Department of Justice conducts an ongoing survey entitled the National Crime Victimization Survey (NCVS). The NCVS data report the number of rapes, sexual assaults, robberies, assaults, thefts, household burglaries, and motor vehicle thefts experienced each year by U.S. residents' age 12 or older and their households. The data are gathered by the Bureau of the Census, under the supervision of the BJS, through interviews in 50,000 households with the respondent who is required to be at least 12 years of age. The NCVS does not inquire about the disability status of the interviewee or anyone in the family during the interview process (Bureau of Justice Statistics, 1999). However, efforts are currently underway in this agency to add children with disabilities to the survey (Personal Communication, Craig Perkins, April 2, 2002).

The National Center for Injury Prevention and Control (NCIPC) defines disabilities as “limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do” (NCIPC, 1999). Surveillance data are collected by the NCIPC on traumatic brain injuries (TBI) and spinal cord injuries (SCI), injuries that can result from criminal victimization as well as accidents. Data are not collected on other disabilities or on children under the age of 16. Data on spinal cord injuries (SCI) indicate that there are approximately 10,000 new injuries per year and that 35% of these injuries are caused by acts of violence (DeVivo, 1997). The traumatic brain injury (TBI) data also suggest that around one-third of injuries are the result of violence with the remaining two thirds attributed to vehicle accidents, falls, and sports related injuries (Harrison-Felix, 1998). These disability related surveillance systems resulting from acts of violence need to be expanded to include other types of disabilities and infants, toddlers, and children from birth to 21 years of age.

The *Statistical Handbook on Violence in America* (Dobrin, Wiersema, Loftin & McDowall, 1996), a compendium of data on violence compiled by the National Research Group at the behest of the National Academy of Sciences Panel on the Understanding and Control of Violent Behavior, is also silent on children with disabilities as victims of crime and child abuse and neglect. The sections on vulnerable groups and situations omit children and adults with disabilities.

Data are not collected on disability status among children who are victims of child abuse and neglect in congressionally mandated national incidence studies. This includes all three national incidence studies mandated by the Child Abuse and Prevention Treatment Act (CAPTA) (P.L. 93-247): NIS-1 (1981), NIS-2 (1988), and NIS-3 (1996). Ironically, although CAPTA also mandated a national study of the incidence of maltreatment among children with disabilities, which was completed in 1993 (Westat, 1993), data on children with disabilities were not included in NIS-3 and are not being gathered in NIS-4. The National Child Abuse and Neglect Data System (NCANDS), which collects compiled child maltreatment data from state agencies on reports, investigations, victims, and perpetrators, is also silent on the disability status of children who are victims of neglect, physical abuse, sexual abuse and emotional abuse.

The lack of data on the victimization of children and youth with disabilities is universal across the major criminal justice and child maltreatment databases mandated, compiled, and maintained by the federal government. This is a major barrier to the understanding of the scope and nature of violence and maltreatment inflicted upon infants, toddlers, children and youth with disabilities. The variety of statutory authorities for the collection of public data sets on the disability and victimization status of children and the absence of a mandate and resources for a comprehensive demographic study of childhood disability across health, education, social service and criminal justice agencies, compound the problem. Children and youth with disabilities need to be included and counted in crime victim and child abuse and neglect national databases.

Prevalence and Nature of Violence Against Children with Disabilities

“Children’s talent to endure stems from their ignorance of alternatives”.

Maya Angelou (1969)

Violence committed against children and youth with disabilities can include conventional violent crimes (i.e., homicide, assault, theft, robbery), child abuse and neglect (i.e., neglect, physical abuse, emotional abuse, and sexual abuse), specialized crimes (i.e., abduction by family member, stranger abduction), family violence (i.e., domestic violence, spouse abuse, step-parent abuse) and noncriminalized violent acts (i.e., assaults by other children, sibling assault, bullying, physical interventions/restraint). Victimization data are available on children and youth with disabilities for child maltreatment, but not for other violent crimes (Sullivan & Knutson, 1998; 2000a; Westat, 1993). However, the Crime Victims with Disabilities Awareness Act, introduced in Congress in early 1998, proposed to include disability status in the U.S. National Crime Victim Survey and mandate research addressing crimes against individuals with disabilities, including children. Unfortunately, this has yet to be realized.

Conventional Violent Crimes

Given the paucity of crime victimization data that are collected on children with disabilities, it is not surprising that minimal research has been conducted on infants, toddlers, children and youth with disabilities as victims of conventional violent crimes, including homicide, assault, sexual assault, theft, and robbery. Although it is likely that there are cohorts of children with disabilities among the existing data sets and research studies including nondisabled children, they remain unrecognized and unidentified in the research literature. A comprehensive literature search was completed by searching each of the conventional violent crimes (i.e., homicide, assault, sexual assault, theft, and robbery) by each childhood disability (i.e., behavior/emotional disability, visual impairment, deaf or hard of hearing, learning disabilities, mental retardation, communication disorders, speech and/or language disorders, health/orthopedic disabilities, physical disabilities, autism, and multiple disabilities) as victims of each conventional crime. Only six citations were identified: two addressing children with disabilities as victims of infanticide, two as victims of sexual assault, and two data based studies involving questionnaires of adolescents and special education teachers. No citations were found addressing children with disabilities as victims of assault, theft, or robbery.

The two citations addressing homicide dealt with a review of the literature of neonaticide, infanticide, and filicide from 1826 to 1994 (Pitt & Bale, 1995) and a discussion of ethical issues created by the ability of advancing medical technology to identify fetuses and infants with disabilities (Cohen, 1990). Pitt and Bale (1995) addressed the presence of severe disabilities as a common motive for infanticide. No data are presented in either citation. The two sexual assault citations are program descriptions. Merkin and Smith (1995) developed a community-based model of services for deaf and deaf-blind victims of sexual assault and domestic violence. Cohene and Cohene (1989) addressed the application of art and writing techniques in therapy for non-signing deaf children and included a case study of a girl who was sexually assaulted to illustrate the application of these therapeutic methods. No data are presented in either sexual assault citation. Using a questionnaire developed to assess student’s concerns and experiences with crime, Bryan, Pearl, and Herzog (1989) found that high school

students with learning disabilities were more likely to be victims of crime (i.e., theft and sexual assault) than nondisabled peers. Interviews with secondary level special education teachers indicated that students with behavior disorders were more likely to be victims of violent crime (i.e., aggravated assault, robbery and rape) than learning disabled or mentally retarded peers (Lang & Kahn, 1986). Weaknesses of these studies include a reliance on questionnaire data, small sample sizes, subject selection biases, and no control groups. Thus, existing data on the criminal victimization of children with disabilities are sparse and limited.

Child Abuse and Neglect Incidence Studies

There have been several studies of the incidence of abuse and neglect among samples of disabled children and adults referred to treatment centers. Sullivan et al., (1991) investigated patterns of abuse among a sample of 482 consecutively referred disabled maltreated children in a hospital setting. Results indicated that sexual abuse or a combination of sexual and physical abuse were the most common forms of maltreatment endured by the referred children with disabilities. The majority of subjects had communication disorders including speech and/or hearing impairments, learning disabilities and cleft lip and/or palate. Males with disabilities were more likely to be victims of sexual abuse than males in the general population and placement in a residential school was identified as a major risk factor for sexual abuse among disabled youngsters. These results were replicated in a 5-year retrospective study of 4,340 child patients in a pediatric hospital in which the majority were victims of sexual abuse (68%) while 32% were victims of physical abuse (Willging, Bower, & Cotton, 1992). Studies in Great Britain (Westcott, 1991), Australia (Turk & Brown, 1992), and Canada (Sobsey & Doe, 1991) have also found that sexual abuse is the most prevalent form of maltreatment among children with disabilities. However, this research is limited by subject selection biases in that most subjects were obtained from hospital, medical treatment centers, or institutions for the disabled, which inherently have large numbers of abused individuals seeking treatment. Accordingly, they may miss large cohorts of neglected children who are not typically referred for treatment.

Prevalence Estimates

The Child Abuse Prevention, Adoption and Family Services Act of 1988 (CAPTA) (PL100-294) mandated the study of the incidence of child abuse among children with disabilities and the relationship between child abuse and disabilities. This charge was given to the National Center on Child Abuse and Neglect (NCCAN), which responded by contracting with Westat, Inc. to conduct the study. Results indicated that 14.1 percent of children in a nationally representative sample whose maltreatment was substantiated by Child Protective Service (CPS) workers had one or more disabilities, which were suspected by CPS workers (Westat, 1993). Data were collected from 35 CPS agencies, which were statistically selected to be nationally representative of U.S. counties. Major findings included: the incidence of maltreatment among children with disabilities was 1.7 times higher than the incidence in children without disabilities; in 47 percent of cases involving children with disabilities, the CPS workers reported that, in their opinion, the disability either led to or contributed to the abuse; in 37 percent of cases, the CPS workers reported that, in their opinion, the abuse contributed to or resulted in a disability; and the children with disabilities were more likely to be white males five years of age or older from one-child families (Westat, 1993). The most

frequent types of disabilities were serious emotional disturbance, learning disabilities and speech or language impairments. However, the authors report that there were great disparities in the definitions of disabilities and only a handful of CPS agencies systematically differentiated between disabled and nondisabled children. The study is a commendable first attempt to empirically derive national prevalence data on maltreatment among children with disabilities. Unfortunately, the study is methodologically flawed in several areas. First, it relied on the opinions of CPS workers to assess and determine disabilities and they have neither training nor expertise in disability diagnosis. Secondly, several analyses on the relation between abuse and disability were based on CPS worker "opinion" as to whether or not the disability played a role in the abuse and/or the abuse caused a disability. Thus, some results were based on opinion rather than empirically derived data. Data on the validity and reliability of these disability determinations were not reported. Thirdly, data were collected for substantiated cases of maltreatment identified during the late winter and early spring of 1991 and, accordingly, are limited by the time sampled for the occurrence of maltreatment. Finally, and most critically, the study limited itself to cases of intrafamilial abuse among CPS agencies and omitted cases of extrafamilial abuse, which are typically found in law enforcement records. This exclusion of cases of extrafamilial abuse in data analyses limits the validity and generalizability of results.

Compounding the paucity of research on the maltreatment of children with disabilities, state agencies charged with the responsibility of investigating or responding to maltreatment do not typically note the presence of disabilities in their records. Bonner, Crow, and Hensley (1997) found that only seven states recorded disability in their abuse records. There are three disability related issues that impinge upon the reporting and recording of child maltreatment: The child's lack of discernment that an event or interaction with an adult is abusive, the child's communication competence which interferes with his or her ability to report the maltreatment to adults, and the adult's decision to not make a formal report because of the child's disability status. While it might seem improbable that victims could be involved in truly abusive interactions without recognizing it, only 25% of samples of adolescent and adult subjects meeting conservative criteria for physically abusive childhood experiences describe those experiences as abusive (Rausch & Knutson, 1991). Moreover, even adolescents who were adjudicated abused are unlikely to label their experiences as physically abusive (Berger, Knutson, Mehm, & Perkins, 1988). In particular, lack of discernment of the abuse in childhood and recognition of the treatment as being abusive in adulthood is a potential factor that needs to be investigated among adults diagnosed with communication related disabilities in childhood. This factor is a potential contributor to an under-representation of children with disabilities in official records of maltreatment. Accordingly, these individuals may self-report the maltreatment in adulthood, if they become aware that the treatment in childhood was abusive. Factors that mitigate and influence the adult retrospective reports of child maltreatment among various disabilities also need to be identified.

Communication problems inherent in many disabilities render children unable to understand and/or verbalize episodes of abuse (Brookhouser, Sullivan, Scanlan & Garbarino, 1986; Knutson & Sullivan, 1993). Such children are unable to report that they have been victimized and absent the unlikely event of an eye witness or a confession, incidents of abuse of children with disabilities do not readily come to the attention of child protective service or law enforcement personnel.

Nonverbal children are at increased risk to be maltreated (Sobsey & Doe, 1991), as are children with disabilities, with limited speech and language skills (Knutson & Sullivan, 1993; 2000a). This research provides support for the notion that children with communication disorders, i.e., speech and language disorders, hearing impairments, and learning disabilities, as a group are at increased risk to be victims of neglect, physical abuse, or sexual abuse in comparison to nondisabled peers. They are also at increased risk to endure multiple forms of maltreatment that include some type of physical abuse. Children with communication disorders who are victims of sexual abuse are more likely to be victimized by family members than extrafamilial perpetrators. The majority of children with communication disorders are maltreated in their own homes by their parents, followed by other family members including step and foster parents, and live-in boy or girl friends of parents (Sullivan & Knutson, 1998). There are differences in the type of maltreatment endured as a function of disability status. Children who are deaf and hard-of-hearing are victims of neglect, physical abuse, and sexual abuse, in descending order of magnitude, whereas children with learning disabilities and speech and language disabilities are victims of neglect, sexual abuse, and physical abuse (Sullivan & Knutson, 2000a).

Prevalence estimates are only as good as the reliability of the information contained in the estimate source. Methods used in determining prevalence rates for nondisabled children cannot simply be applied to determine accurate prevalence estimates among children with disabilities. Different informational levels exist for the disabled population and methods of accessing them need to be identified by epidemiologists.

Epidemiological Studies

Two studies have addressed the prevalence of maltreatment among children with disabilities and included a nondisabled control group. These include a hospital-based epidemiological study, which identified associations between child maltreatment and disability status and a school-based study, which expanded on those associations and identified adverse outcomes of the maltreatment.

The hospital-based epidemiological study (Sullivan & Knutson, 1998a) entailed the merger of over 39,000 hospital records with Central Registry, foster care, and law enforcement databases resulting in over 6,000 matches and a maltreatment prevalence rate of 15%. Both intrafamilial and extrafamilial maltreatment records were included. Among the children identified as maltreated, 64% were found to have some type of disability in contrast to 32% of the nonabused children in the comparison group. The identified disabilities, in descending order of magnitude, were: Behavior disorders (37.8%), speech/language disorders (8.7%), mental retardation (6.2%), hearing impairment (6.1%), learning disability (5.7%), other disabilities (4.1%), health impairments (2.4%), and Attention Deficit Disorder, without Conduct Disorder (1.6%). Disability status was determined from a review of hospital records. Types of maltreatment, in descending order of magnitude, most frequently experienced by the children were neglect, physical abuse, and sexual abuse. In addition, over half of the sample (54%) endured multiple forms of maltreatment. There were slightly more males (56%) than females (44%). The maltreated children were 2.2 times more likely to have a disability than nonabused children. Certain types of disabilities were found to be at risk for certain types of maltreatment. Children with behavior disorders, speech/language disorders, and mental retardation were at increased risk for neglect. Behavior disorders, hearing

impairment, and mental retardation were high-risk disabilities for physical abuse. Children with ADD/HD without Conduct Disorder, behavior disorders, learning disabilities, and mental retardation were at increased risk for sexual abuse. Children with behavior disorders and mental retardation were at increased risk for all three forms of maltreatment. This research provided suggestive evidence that behavior disorders and mental disabilities are both a risk and a consequence of maltreatment. Future research needs to identify characteristics of the youth who are early starters in sexual and physical violence as well as those who continue in a pattern of criminal activity (e.g., Moffit, 1993; Moffit, Caspi, Dickson, Silva, & Stanton, 1996).

The school-based epidemiological study (Sullivan & Knutson, 2000a) was a conceptual replication of the hospital-based research with a school-based data pool and permitted prevalence estimates of abuse among children with disabilities based upon standard definitions of maltreatment and homogeneous education-based definitions of disabilities. This research entailed the merger of almost 50,000 records from Omaha Public (39,800) and parochial (10,068) school children matriculated during the 1994-95 school year with Nebraska Central Registry, Foster Care Review Board, and Omaha Police records of child maltreatment. A review of the records of maltreatment of 4,954 children across the social service and police agencies involved in the merger with school records indicated an 11% prevalence rate of maltreatment among the Omaha Public Schools and a 4.5% prevalence rate among the parochial schools. Among the maltreated children without a disability, 9% were victims of maltreatment. In contrast, 31% of the children with an identified disability had records of founded maltreatment in either social service or police agencies. Disability types for the maltreated children are given in Table 1. Table 2 provides the percentage of maltreated children among each disability group. The relative risk for maltreatment among children with disabilities is 3.44 times that of nondisabled children. The relative risks for neglect, physical abuse, emotional abuse and sexual abuse, respectively, for the disabilities are as follows: Behavior disorders (6.7, 7.3, 7.0, 5.5), mental retardation (3.7, 3.8, 3.8, 4.0), learning disabilities (2.0, 2.0, 2.0, 1.8), health impairments (3.4, 3.3, 3.4, 2.0), speech/language disorders (4.7, 4.7, 6.6, 2.9), physical disabilities (1.8, 1.2, 2.5, 2.0), and hearing impairment (2.3, 3.8, 2.0, 1.2). Overall, there was a strong association between disabilities and neglect, with disabled children being 3.75 times more likely to be victims of neglect than children without disabilities. Children with behavior disorders and mental disabilities were significantly more likely to be neglected than children with other disabilities.

Maltreatment and disabilities were associated with other behavioral and social insults including additional stressful life events not identified as the specific maltreating episode. These social insults included parental alcohol and drug abuse, mental illness, disability, and single parent homes. Domestic violence was a co-occurring factor in the maltreatment histories of both disabled and nondisabled children. Behavior disorders, mental disabilities, and speech/language disorders were the primary types of disabilities among the disabled maltreated children with a record of domestic violence in their families. Given maltreatment and a record of domestic violence in the home, there is a significant association between disability status and being a victim of physical abuse and neglect. Age at first incidence of maltreatment is significantly younger for disabled (5.4 years) and nondisabled (6.6) children with records of domestic violence than both disabled

(8.2) and nondisabled children (8.8) children with no record of domestic violence. Severity levels of maltreatment type increased as a function of the presence of domestic violence in the home for both disabled and nondisabled children. Significantly more disabled children with records of domestic violence become physical perpetrators than nondisabled children with domestic violence in the family. There is a need for prospective research related to domestic violence and disability status.

Maltreated Children with Developmental Disabilities

While children with developmental disabilities have received the most attention in the general research literature on disabilities, this has not been the case in the research literature addressing maltreatment and disabilities. Therefore, specifically for this paper, those children and youth with developmental disabilities from the school based epidemiological study were analyzed as a group for various maltreatment parameters. Among the 4,954 maltreated children, there were a total of 818 children with some degree of mental retardation: mild ($n=593$), moderate ($n= 160$), and severe/profound ($n = 65$). Some 237 of these children, or almost thirty percent (29.0%), had records of some form of maltreatment. Among the 593 children with mild mental retardation, one third (31.7%) were maltreated compared to slightly over one fifth (22.5%) of the 160 children with moderate mental retardation and one fifth (20.0%) of the 65 children with severe/profound mental retardation. This is consistent with Benedict and colleagues (1990) who found the most severely delayed children to be at less risk than those with higher intellectual functioning (Benedict, White, Wulff & Hall, 1990). It is important to note that almost two-thirds (65.8%) of the maltreated children with mental retardation experienced multiple forms of abuse. The remaining third (34.2%) experienced one type of maltreatment. The four types of maltreatment in descending order of magnitude experienced by the children were: Neglect (83.1%), physical abuse (51.5%), emotional abuse (41.4%), and sexual abuse (38.4%). These numbers do not sum to 100 because of the multiple forms of maltreatment endured by the majority (65.8% of the children). More boys (56.5%) experienced maltreatment than girls (43.5%) with mental retardation. Several family risk factors for maltreatment were identified in the maltreatment records of the children including: domestic violence, having a parent who had been a victim of maltreatment, having a parent that is ill or disabled (specific disability not identified), and living in single parent homes. Some 16.5% of the maltreated children's families had records of domestic violence. One fourth (27.0%) of the parents of maltreated children with mental retardation had been victims of maltreatment themselves. One fifth (21.0%) of the parents of maltreated children with mental retardation had a disability or chronic illness. The majority (80.2%) of these maltreated children lived in single parent homes. An immediate family member most often committed maltreatment of children with mental retardation. Almost ninety percent (88.6%) of the maltreated children with mental retardation were maltreated by an immediate family member. Some 16% had been victims of maltreatment by an extended family member. Extra-familial perpetrators accounted for thirty percent (29.5%) of the maltreatment. Again, the above percentages do not sum to 100 because the majority of these children endured multiple forms of maltreatment from multiple perpetrators. Sexual behavior problems were prevalent in slightly over ten percent (11.3%) of maltreated children with mental retardation. Less than three percent (2.5%) of maltreated children with mental retardation became sexual perpetrators. Five percent (5.4%)

of maltreated children with mental retardation became perpetrators of physical abuse. The median income for families of maltreated children with mental retardation was \$20,436.76. The poverty line established for a family of four in 1995 was \$15,569. Families of maltreated children with mild mental retardation had a median income of \$20,059.16, compared to \$22,065.06 among the families of maltreated children with moderate mental retardation, and \$21,215.92 among the families having maltreated children with severe/profound mental retardation. Some 14% of the maltreated children with mental retardation had family incomes below the poverty line compared to less than 1% (.005%) of their nonmaltreated peers.

Non-criminalized Child Abuse and Neglect

Not all child abuse and neglect attains a severity level that can be categorized as a crime, either misdemeanor or felony. Some child abuse and neglect is bad parenting and represents poor judgment in the care and tending of children. A complete discussion of lines of demarcation between the two is beyond the scope of this paper. In general, state statutes typically codify felonious and misdemeanor child maltreatment within the criminal codes and “bad parenting” within the juvenile codes of the laws of their respective states. Since prosecutors retain discretion regarding what charges to file, some felonious child abuse is prosecuted under state juvenile codes when the degree of violence and abuse perpetrated against the child met criteria within the criminal codes. This illustrates the need for comprehensive multidisciplinary models involving health, welfare, and justice professionals in the conceptualization of child maltreatment (e.g., The Interagency Research Committee on Child Abuse and Neglect). Legal definitions interpreted at the discretion of prosecutors given the realities and probabilities of convictions are inadequate to distinguish between child abuse and neglect that is a crime and that which is “bad parenting” and poor parental judgement.

Accordingly, it is not surprising that attempts to locate research studies discussing this issue that included children and youth with disabilities were unsuccessful. In an attempt to provide some preliminary data on the topic, the severity levels of neglect (Table 3), physical abuse (Table 4), and sexual abuse (Table 5) used during archival record reviews in police and social service agencies with a hospital sample of maltreated children with disabilities (Sullivan & Knutson, 1998a) and a school based population of disabled and nondisabled victims of maltreatment (Sullivan & Knutson, 2000a) were examined by classifying the four respective severity levels of maltreatment as meeting criteria for the criminal and/or juvenile codes of Nebraska for child abuse and neglect. The juvenile codes were operationally defined as “bad parenting”. It should be noted that four research assistants trained in the record review procedures employed in the original research made these determinations. This provided some consistency between the coders of the severity levels of maltreatment in the original research and the categorization of the three sets of maltreatment severity levels as meeting criteria for child abuse and neglect defined in the criminal and juvenile codes in Nebraska. Also, the percentages in each severity category represent means of both multiple episodes of maltreatment and are collapsed across all disability categories used in the research. Thus, only preliminary notions regarding this distinction among abused and neglected children with disabilities are discernable.

The following severity levels were determined to meet the Nebraska Juvenile Codes for noncriminal child abuse and neglect: Neglect (1, 2 and 3); Physical

Abuse (1 and 2); and Sexual Abuse (1). The remaining respective severity levels were categorized as criminal child abuse and neglect: Neglect (4); Physical Abuse (3 and 4); and Sexual Abuse (2, 3, and 4).

The severity levels for all three forms of maltreatment endured by the 2,209 abused children with disabilities in the hospital sample (Sullivan & Knutson, 1998) are given in Table 6. The vast majority of the neglect (86%) and physical abuse (87%) were noncriminal in nature compared to only 11% of the sexual abuse. Thus, in the hospital sample almost 90% of the sexual abuse but only 11% of the physical abuse and 14% of the neglect were classified as criminal child abuse. In the school-based population (Table 7) of 1,012 maltreated children with disabilities, almost all of the neglect (96%) and physical abuse (85.7%) were noncriminal compared to only 5.3% of the sexual abuse. For the 3,491 nondisabled children and youth, similar percentages were found. It is noteworthy that significantly more disabled children endured the highest severity level of sexual abuse.

Unfortunately, it is not possible to make linkages between these incidents of maltreatment and their disposition in the criminal justice system. Future research needs to identify these differences in disabled and nondisabled children.

Specialized Crimes

Specialized crimes against children and youth can take the form of stranger abduction, abduction by family members, domestic assaults, and running away from home. As in the case of conventional violent crimes, victim data on children and youth with disabilities are not collected and there has been minimal research addressing specialized crimes that included them as subjects.

The Office of Juvenile Justice and Delinquency Prevention (OJJDP) commissioned a study on missing, abducted, runaway, and thrown away children in the U.S. in 1990 (Finkelhor, Hotaling & Sedlak, 1990). The methodology relied primarily on telephone interviews with households and juvenile facilities. The telephone interview did not collect data on disability status of the youth. However, 13 runaways were captured in eight schools for the physically and/or mentally disabled. The estimated prevalence rate of juveniles with disabilities running away from these placements was less than 1 per 1,000. Since the vast majority (95%) of children and youth with disabilities between 1988 and 1993 were educated in mainstreamed or full inclusion educational settings (Kaye, 1997), no inferences regarding the prevalence of runaway status among children and youth with disabilities may be generated from the research.

The prevalence of disabilities among runaways in a hospital and school population was examined (Sullivan & Knutson, 2000b). There were a total of 255 runaways among the 39,353 hospital records (Sullivan & Knutson, 1998a) and 562 runaways in the total school population of 40,211 children and youth (Sullivan & Knutson, 2000a). Children and youth with disabilities were at increased risk to become runaways in both populations and the presence of maltreatment significantly increased the association between running away and disability status. The prevalence rate of disabilities among the maltreated runaways was 83.1% and 47% among the nonmaltreated runaways in the hospital sample and 34% and 17%, respectively, in the school sample. Children with behavior disorders, mental retardation, and some type of communication disorder were significantly more likely to run away than children with other disabilities. Among the maltreated runaways with and without disabilities, physical abuse and sexual abuse were

significantly associated with running away. Records of domestic violence were more prevalent in the families of runaways with behavior disorders and no diagnosed disability. Lower academic achievement, poor school attendance, and more family stress factors were associated with maltreatment and disability status. It is highly probable that there are large cohorts of unidentified and unrecognized adolescents with disabilities within the subject populations of the dating violence research, which is essentially silent on people with disabilities. Early work identified a domestic violence problem within the Deaf community (Egley, 1982). Dating violence, including date rape, have been covered in the popular press (e.g., *People Magazine*, see Parrell, 1994), but not in the scientific literature, as being significant problems at Gallaudet University in Washington, DC, a government supported institution with a predominantly Deaf and hard-of-hearing student population. In 1994, a total of 60 known rapes were committed in a 15-month period among the 1148 women on the campus (Parrell, 1994). This rate is essentially 60 women per 1,000, 5 times the rate of 12 women per 1,000 between the college ages of 18-21 years in the National Crime Victimization Survey (Perkins, 1997). The Deaf culture/community is paternalistic and male dominated (Dolnick, 1993) and Deaf and hard-of-hearing children and youth are at greatest risk to be physically abused (Sullivan & Knutson, 1998b). These factors may account for the higher rates of dating coercion observed in this population. As in the hearing community, a shroud of silence engulfs domestic violence issues within the Deaf and hard-of-hearing community. Sullivan (1998) reported that one in five maltreated children with disabilities has a record of domestic violence in their families and domestic violence is associated with both neglect and physical abuse. Significantly more maltreated children with disabilities with records of domestic violence have parents with an alcohol or drug problem than maltreated nondisabled youth with records of domestic violence. This preliminary evidence and the lack of identification of disabled samples in previous research underscores the need for research elucidating the chain of causation and risk for dating and later spousal violence among maltreated children and youth with disabilities and the mitigating influences of alcohol abuse.

No citations were identified addressing stranger abduction, abduction by family members or bias crimes committed against children and youth with any type of disability. Although these are low baserate events in the nondisabled population, efforts to identify the prevalence of these crimes among children and youth with disabilities need to be undertaken.

Noncriminalized Violent Acts

Noncriminalized violent acts encompass assault by peers, sibling assault, bullying, and condoned physical interventions that can escalate to abuse. Again, no victimization data are collected on children with disabilities for noncriminalized violent acts and there is a paucity of published studies including children with disabilities as subjects in research addressing these issues. Sibling abuse has been addressed in nondisabled samples including physical assault and incest (*Virginia Child Protection Newsletter*, 1993; Wiehe, 1996).

In a hospital based epidemiological study, Sullivan and Knutson (1998a) identified a peer physical abuse rate of 2.6% among disabled victims. Sibling abuse was grouped with stepparent physical abuse and, taken together, accounted for 10% of the physical abuse of the children with disabilities. Peers accounted for almost 10% of the sexual abuse of the children with disabilities and siblings and

stepparents, grouped together, accounted for 10.8 percent. Deaf and hard-of-hearing children in residential placements are at high risk to be physically and sexually assaulted by older students and peers (Sullivan & Knutson, 1998b). These preliminary data illustrate the need to identify the incidence and parameters of peer and sibling abuse among samples of children and youth with disabilities.

Bullying of children and youth with disabilities has been addressed empirically in the United Kingdom and other European countries (Dawkins, 1996; Roland & Munthe, 1989). Defined as physical and/or psychological teasing, name-calling, hitting, pushing, social exclusion, threats, extortion, and theft, bullying is considered to be a form of peer abuse (Dawkins & Hill, 1994). Children enrolled in special education programs associated with visible disabilities (i.e., cerebral palsy, blindness, deafness, etc) are twice as likely to be bullied than children with disabilities not associated with visible physical conditions (i.e., learning disabilities, behavior disorders) and some one-third of these children are regularly bullied at school with boys being bullied more than girls (Dawkins, 1996). These results are consistent with other research which has found children with special education needs twice as likely to be bullied than those in regular class placements (Olweus, 1991; Whitney, Nabuzoka, & Smith, 1992).

Condoned physical interventions dispensed under the guise of therapeutic interventions implemented with children with disabilities that can escalate to abuse are also noteworthy and deserving of attention. Examples include physical restraint, holding, and corporal punishment in special education settings. Some dentists use controversial techniques to control uncooperative children, including children with disabilities, in the dental chair. Hand-over-mouth (HOM) and hand-over-mouth with airway restriction (HOMAR) are procedures taught in dentistry textbooks and are standard techniques supported by the American Dental Association. A survey completed by The Journal of Dentistry for Children (Braham, Tsuchiya, Kudosu, & Fukuta, 1994) indicated that 73% of the respondents had used HOMAR. The procedure entails using airway restriction to quiet the child while the dentist speaks quietly and firmly into the child's ear, indicating that the hand will be removed if the child becomes quiet. Physical restraint of children and youth by professionals in psychiatric and group home facilities is another controversial technique that can escalate to abuse and result in physical injury to the child or youth. The Joint Commission on the Accreditation of Hospitals (JCAH) has published guidelines on the use of physical restraint with children in psychiatric hospitals. These guidelines did not include children and youth with disabilities as a special group in the standards. Children with disabilities in regular education programs are sometimes physically restrained by teachers and teacher aides. Corporal punishment is permitted in 22 states in the U.S. and includes the physical striking of children and youth with disabilities within the public schools (American Academy of Pediatrics, 2000).

There is a need for data on the prevalence, nature, and effect of these noncriminalized violent acts committed against children and youth with disabilities by peers, siblings, schoolmates, and professionals charged with their care and welfare. Currently, it is unknown if children and youth with disabilities have a higher base rate of these types of violence than nondisabled peers.

Disabilities as a Consequence of Criminal Victimization

Disabilities can also result from the experience of violence or some form of child maltreatment. Data are limited on the prevalence of acquired disabilities given

the problem of determining the temporal association between the onset of the disability and the occurrence of the violent act. Limited epidemiological data are available on spinal cord injuries resulting from violence, particularly firearm injuries (Waters, Cressy & Adkins, 1996). Although it is known that one third of spinal cord injuries are the result of intentional violence, the pre-existing disability status of adolescent victims 16 and older is unknown and uncaptured in the spinal cord injury databases. Ethnicity and socioeconomic data, gender and rural/urban status are gathered on victims, however. A population based study of pediatric firearm injuries over a one-year period, identified an 11.7% mortality rate and a 10% permanent disability rate (Dowd, Knapp, & Fitzmaurice, 1994). The disabilities were physical disabilities and no data were available on the premorbid disability status of the children who ranged in age from birth to 16 years. Traumatic brain injury is the most devastating type of pediatric trauma and an estimated 50,000 children and adolescents each year sustain permanent disability resulting from brain injury (Stylianou, 1998). However, follow-up data on the nature and extent of the child's disability status typically does not occur beyond the resolution of the acute trauma. No studies assessing the nature and extent of disabilities resulting from maltreatment, including neglect, physical and sexual abuse, were identified in the extensive literature search conducted for this review. There is suggestive evidence that behavior disorders (Knutson & Schartz, 1997; Sullivan & Knutson, 1998; 2000a) and mental retardation (Sullivan & Knutson, 1998; 2000a) may be consequences of maltreatment. However, the data are only suggestive and more controlled research addressing this issue is needed.

A descriptive epidemiology of violence related disabilities in children from birth to 21 is urgently needed. It is no longer sufficient to measure only the infant and child mortality outcomes of violence. Disability status as a potential outcome of violence and maltreatment inflicted upon children also needs to be captured in relevant public health surveillance systems.

Institutional Abuse

The problem of maltreatment of children in institutions is long-standing and has been reported for over two centuries. Sobsey (1994) provides a review of abuse in institutions which house children and adults with disabilities. Sullivan, Vernon and Scanlan (1987) found that, among deaf youth attending residential schools, sexual abuse tended to occur in bathrooms, bedrooms and specialized transportation. Evidence from residential placement facilities suggests that children with sensory impairments may be at increased risk for maltreatment (Brookhouser, 1987; Whitaker, 1987). Numerous states in the U.S. and provinces in Canada have had major child abuse investigations in residential schools and institutions for children who are deaf and hard of hearing, children with visual impairments, and children with developmental disabilities (Brookhouser, 1987; Sobsey, 1994; Sullivan & Knutson, 1998). High rates of maltreatment have been identified among deaf and hard of hearing youth attending residential schools (Sullivan & Knutson, 1998; Sullivan, Brookhouser & Scanlan, 2000). Although children who are deaf and hard of hearing are significantly more likely to be maltreated by immediate family members, placement in a residential school is a risk factor for physical and sexual abuse. A residential placement is a major risk factor for experiencing sexual and/or physical abuse, the primary location is the dormitory, and the primary perpetrators are houseparents, older students, and peers (Sullivan, Vernon & Scanlan, 1987; Sullivan & Knutson, 1998; Sullivan,

Brookhouser & Scanlan, 2000). Furthermore, for males, this type of placement coupled with physical and sexual abuse has an increased risk for alcohol abuse, increased behavior management problems, and the perpetration of sexual and physical abuse against peers (Sullivan & Knutson, 1998). These factors may contribute to the high base rate of sexual assault and date rape identified at Gallaudet University (Parrell, 1994). The cultural silence that surrounds this sexual abuse in residential schools for the deaf has been documented (Mertens, 1996) and is a formidable barrier to conducting research, developing and evaluating prevention programs, and in identifying mediators and moderators in the development and maintenance of abusive environments in state supported residential schools for deaf and hard of hearing children and youth.

These data, and highly publicized episodes of abuse at residential facilities (Tiechrobe, 2001) suggest that current institutional practices, including condoned physical interventions, which can escalate to abuse and inadequate sex education, may also play contributory roles in the maltreatment of children and youth with disabilities who reside in institutions. Considerable attention was afforded the institutional abuse of children by the federal government in the late 1970's and early 1980's. Research on institutional abuse funded by NCCAN during the early 1980's included the following findings: institutional child abuse stems from complex interactions of human, institutional, and fiscal problems (Blatt & Brown, 1986; Shaughnessy, 1984); willingness to report abuse of a child or youth in an institution was significantly related to the type of abuse (physical and/or sexual) and commitment of the staff member to the overall well-being of the residents (Rindfleisch & Bean, 1988); judgments of severity levels of institutional abuse and neglect by staff tend to be lower than the actual severity levels, i.e., staff tend to judge abusive events as harmful rather than as abusive (Rabb & Rindfleisch, 1985); recommendations for child abuse prevention and protection of children and youth residing in institutions were published based on survey data from 50 states in 1978 (Rindfleisch & Hicho, 1987); and, a post-substantiation model for investigating allegations of institutional abuse was published which included the development of an evaluation team and components of the evaluation itself which encompassed treatment issues, a child profile, staff issues, staff training, physical plant issues, education, abuse related issues, and the role of the state's child protection agency (Kelleher, 1987). Concern was expressed at this time regarding the willingness of administrators and staff of residential institutions to recognize, identify and report child abuse and neglect within the institution. Similar concerns and attitudes appear in the current literature on institutional abuse of the disabled (Sobsey, 1994; Sullivan & Knutson, 1998; Sullivan, Brookhouser & Scanlan, 2000).

Institutional abuse is a perennial problem and given the numbers of children and youth with disabilities housed in institutions, the prevalence, nature, and risk factors for violence and abuse within residential facilities need to be determined.

Policies and Programs

“It’s a mistake to blame people in the systems, but it is not a mistake to look hard at the systems within which we operate and then to say, “It’s not good enough, it’s too late, too little of one thing, too much of another.” We have to commit ourselves to a zero tolerance policy regarding maltreatment of children. Until that sense of rage rises up in us, we will continue to say, “We’re doing all right.” I think we’re not doing all right. Less able is not less worthy”. Rud Turnbull (1994)

There is no public policy blueprint or initiative addressing violence and abuse of infants, toddlers, children and youth with disabilities. The Panel on Research on Child Abuse and Neglect of the National Academy of Sciences set forth a national child-oriented research agenda which included a wide range of recommendations for policy, practice and research (National Research Council, 1993a). Understanding Child Abuse and Neglect (National Research Council, 1993a) established the National Research Council’s agenda for research addressing child maltreatment but failed to include children and youth with disabilities and issues pertaining to their maltreatment. Of even greater concern, is the neglect of children and youth with disabilities in a compendium addressing research, practice and policy in child neglect (Dubowitz, 1999), the most prevalent form of child maltreatment. Furthermore, the violence public policy literature is silent on child and adult victims with disabilities. Two seminal works on violence compiled by the National Research Council, Understanding and Preventing Violence (1993b) and Understanding Violence Against Women (1996), are silent on disability status of both victims and perpetrators. Furthermore, addressing disability status is absent from the research agenda to address domestic violence proposed in both volumes. There is only one reference to domestic violence among summaries of some 1,486 disability-related articles and books (Sobsey, Wells, Lucardie, & Mansell, 1995). Melling (1984) described spousal abuse among the deaf community, the communication problems experienced by deaf female victims, and the response of professionals to deaf victims. No original data were included. The Disabled Persons Protection Commission Hotline in Massachusetts gathered data on callers that suggested some 40% of the reports involved the abuse of disabled persons by family members. A survey of women with physical disabilities indicated that 62% had experienced some form of abuse in their lives, primarily by family members (Young, Nosek, Howland, Chanpong, & Rintala, 1997). However, these data are compromised by subject selection biases and omitted women with other types of disabilities. Currently, there is a critical gap in the research knowledge base on the epidemiology of people with disabilities who become victims of domestic violence as well as those who become disabled by such violence. This gap was a major impediment to the inclusion of violence related objectives for children and adults with disabilities in Healthy People 2010. Future Healthy People volumes will require data driven objectives and the research to provide them needs to be completed.

Although children and youth with disabilities are at increased risk to be victims of crime, particularly child abuse and neglect, there is a surprising paucity of training/continuing education materials for legal professionals, judges, prosecutors, Guardians ad Litem, public defenders, and police officers, on the special needs and vulnerabilities of children and youth with disabilities within the criminal justice system. Needs assessment research has determined that these professionals as well as parents of disabled children are not only aware of their need for training but are receptive to receiving it (Orellove, Hollahan, & Myles,

2000). Children with disabilities are a heterogeneous group and disabilities are not commensurable. They differ according to vulnerabilities for victimization, cultural issues, special communication, including speech and language considerations, disability-specific characteristics, accessibility requirements, and resources for information and/or assistance in meeting their unique needs. All of these factors are critically important in providing appropriate support to crime victims with disabilities within the legal system. In fact, this support must be disability specific. Many misconceptions exist about people with disabilities and it is critical that they not be lumped together into one large mass with the assumption that a given training will fit all disability types. Many existing prevention programs developed for children with disabilities are not based upon empirically derived risk factors and, more importantly, neither have outcome data nor plans to obtain it on either efficacy or effectiveness. A review of five recently funded school based prevention programs targeting children with disabilities have no outcome data on the developed programs. Given the substantial increases in the prevalence of child maltreatment, there is a critical need for prevention-based research to guide public policy and service providers.

Future Research Addressing Violence Against Children with Disabilities

“One can never consent to creep when one feels the impulse to soar”. Helen Keller (1903)

There are several significant challenges in the conduct of violence and maltreatment research among children with disabilities. Firstly, crime victimization and child maltreatment can be both risks and consequences of disability status. Secondly, violence, crime, maltreatment, and disability types are not commensurable. That is, risk factors and consequences vary as a function of the type of crime, the type of maltreatment, and the type disability. Thus, some disabilities are risks for maltreatment and others result from it. Well-controlled methodological studies that compare the maltreatment of children with genetically determined disabilities with children with acquired disabilities compared to nondisabled children are needed. This would assist in addressing a central debate in the disability maltreatment literature, namely the temporal relationship between the onset of the disability and the occurrence of maltreatment and the resulting problems in identifying causal linkages. Prospective studies with the capability of identifying age of onset of the disability and the age at first maltreatment are a potential means of investigating these questions.

The inability to link data from disability sources to child maltreatment, criminal justice, and health related databases hampers research efforts. Both public schools and the Social Security Administration have disability databases on children and youth that could assist in research in determining prevalence rates of disabled child victims of crime by permitting data mergers of the names of child crime victims with these databases to identify the number of disabled children. Federal law does not permit these mergers (i.e., Family Education Right to Privacy Act-FERPA and the Social Security Act). Methods congruent with federal statutes need to be identified to permit this research.

The silence of institutions including federal and state governments in establishing a national public policy and research agenda addressing violence and abuse of children and youth with disabilities is a major barrier to addressing the problem. A national public policy blueprint addressing violence and abuse against children

with disabilities needs to be developed. Children and youth with disabilities need to be included in public policy, practice, and research recommendations in the violence and child maltreatment domains. A comprehensive demographic study of the disability status of children in the U.S. needs to be undertaken through the establishment of a disability research institute for children designed to obtain accurate prevalence estimates, establish definitional standards, promote research on disabled children, and facilitate linkages between disability data sources.

Available data on violence against children and youth with disabilities are scattered, varied in quality, and difficult to access and use. Children with disabilities need to be included in national criminal justice victim databases. Data should be maintained on children with disabilities between the ages of birth and 21 years. Researchers addressing violence and abuse of children with disabilities should have access to these databases. Disability review teams need to be established at the state level to review victims of violence and abuse and determine if any disabilities have resulted from that victimization. These data should be maintained in the vital statistic registries of states and made available to researchers.

Data on disabilities in abuse have been tainted by inconsistent operational definitions of maltreatment, poorly defined heterogeneous populations with disabilities, and questionable validation procedures for determining disabilities (Ammerman, Van Hasselt, & Hersen, 1988; Knutson, 1988; Knutson & Schartz, 1997). This problem is additionally compounded by innumerable underreported incidents of maltreatment by professionals and lay persons to the appropriate agencies. Definition standards of disabilities among children and youth need to be established.

The ontogenesis of behavior disorders and its teleological relationship to circumstances of maltreatment need to be investigated among both boys and girls. There is a circularity of association between maltreatment, the diagnosis of behavior disorders, and the occurrence of physical and sexual violence. Children and youth who exhibit physical and/or sexual aggression will almost certainly be diagnosed as behavior disordered. Although the maltreatment may not occasion the diagnosis of behavior disorder itself, it is possible that the behavior disorder occasions a portion of the maltreatment. Furthermore, the subsequent manifestation of antisocial behavior may co-vary as a function of maltreatment and disability status. These covariates as well as moderators and buffers to the development of violence need to be identified.

Finally and importantly, a conceptual theoretical framework postulating explanations of the violence committed against children with disabilities needs to be developed and evaluated. This framework is urgently needed to guide research efforts in formulating specific hypotheses and designing research studies to address them. Such a framework, and the validation of hypotheses derived from the constructs within it, will result in a better understanding of the relationship between disabilities and different forms of violence, guide the design of prevention and intervention programs, and thereby impact public policy and service delivery.

Table 1: Percentage of Disabilities Among Maltreated Children

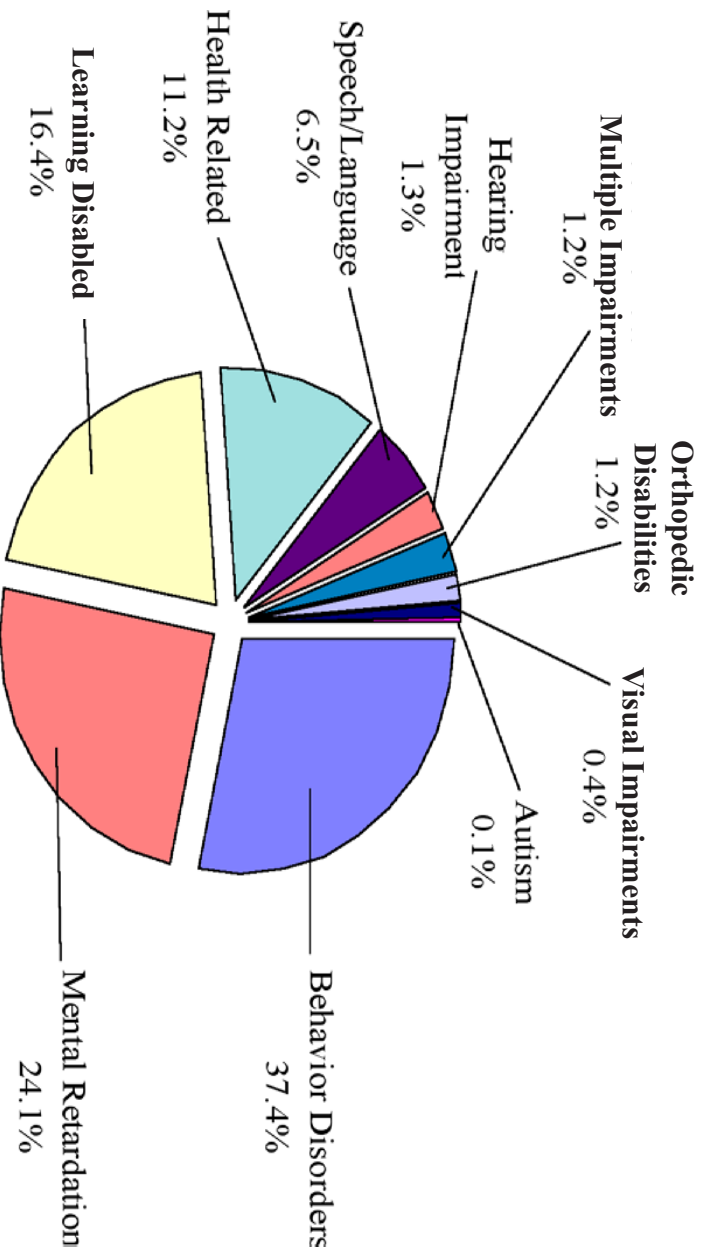


Table 2: Prevalence of Maltreatment by Disability Status

Disability Status	Percent Maltreated
No Disability	9.0%
Behavior Disorders	54.2%
Speech Language Disorders	36.5%
Mental Retardation	29.0%
Other Health Impairment	26.4%
Hearing Impairment	21.3%
Learning Disability	17.7%
Physical Disability	12.6%
Visual Impairments	12.5%
Multiple Impairments	12.5%
Autism	8.3%

Table 3: Severity of Neglect

1. Failure to educate or follow medical recommendations.
2. Non life-threatening lack of supervision and follow-through.
3. Lack of adequate food, housing, and medical care.
4. Life-threatening.

Table 4: Severity of Physical Abuse

1. Potentially injurious to child.
2. Tissue damaging event, harmful restraint or control.
3. Serious injury requiring medical or dental services.
4. Fatality or life-threatening physical event.

Table 5: Severity of Sexual Abuse

1. Witnessing sexual abuse.
2. Fondling (being forced).
3. Oral/genital/digital penetration; genital without penetration.
4. Anal/vaginal intercourse/penetration.

Table 6: Duration of Maltreatment

1. One episode
2. Less than 1 year
3. 1 to 3 years
4. More than 3 years

**Table 7:
Distribution – Severity of Abuse in a Hospital Based Sample**

Severity Level	Sexual Abuse	Physical Abuse	Neglect
1	11%	34%	2%
2	24%	53%	33%
3	22%	9%	51%
4	43%	4%	14%

**Table 8:
Distribution – Duration of Abuse in a Hospital Based Sample**

Duration Level	Sexual Abuse	Physical Abuse	Neglect
1	50%	45%	32%
2	19%	11%	12%
3	15%	16%	17%
4	16%	28%	39%

**Table 9: Distribution – Severity of Abuse
School Based Study (% within abuse category)**

Severity Level	Sexual Abuse		Physical Abuse		Neglect	
	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)
1	6.7%	2.6%	10.7%	29.4%	.05%	0.2%
2	20.6%	17.2%	16.1%	28.8%	19.8%	38.4%
3	9.7%	9.6%	4.3%	8.4%	10.4%	26.9%
4	13.1%	20.4%	0.8%	1.5%	1.5%	2.7%

**Table 10: Distribution – Duration of Abuse
School Based Study (% within abuse category)**

Duration (Months)	Sexual Abuse		Physical Abuse		Neglect	
	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)	(Non-disabled/ Disabled)
0	37.1%	50.1%	26.5%	65.6%	25.2%	57.4%
1-6	2.3%	2.3%	1.0%	2.5%	2.4%	5.6%
7-12	1.0%	1.7%	0.3%	1.0%	0.6%	2.0%
13-18	0.8%	0.8%	0.2%	0.4%	0.5%	1.4%
19-24	0.4%	0.6%	0.1%	0.2%	0.3%	0.8%
24+	1.3%	1.6%	0.6%	1.6%	1.0%	2.7%

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INTERVENTIONAL APPROACHES FOR CHILDREN WITH DISABILITIES WHO ARE VICTIMS OF VIOLENCE

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Executive Summary

In order for children with disabilities to have maximum opportunities, their environment must be safe enough for them to develop without the likelihood of exploitation, violence or severe additional injury. Instead of being given opportunities to maximize their potential, history reveals repeated problems of protecting children with disabilities from being targeted for additional harm. Understanding the nature of child maltreatment generally provides a useful foundation for understanding violence to children with disabilities. However, there are many additional risks to be considered and barriers to intervention relating to the problem of violence against children with disabilities as compared to children without disabilities.

During recent decades, advocates have succeeded against many odds in expanding the world for children with disabilities. The population of children found in schools, in other public settings, and social activities of many types has expanded enormously in its diversity. Greater participation in larger arenas of life for children with or without disabilities carries with it greater exposure to trauma of many different types. Parents and professionals alike view risks as inevitable aspects of greater participation, as long as the risks to which children are exposed are reasonable.

Much remains to be done to analyze and reduce the risk of violence to children with disabilities. A first step is to recognize that the problem of child maltreatment is extensive for all children, and children with disabilities are not exempt from abuse or neglect. Across the U.S. more than 800,000 children were estimated to be confirmed victims of child abuse or neglect in 1999.¹ A one year study of all confirmed child maltreatment diagnosed at a Children's Hospital during 1994 found that 21% (of 812 for whom records were available) "were deemed to be developmentally disabled or delayed before their abuse" and 56% (420 of 812) were behaviorally disturbed.² Other studies have found that as many as 64% of abused children³ to as few as 14% of abused or neglected children⁴ had a disability depending on the populations studied.

While there has been success in identifying children with disabilities who were victimized by abuse, available figures may well under represent the full risk of abuse or neglect. The science and art of proving trauma that is physical, sexual or emotional in nature are still young. The less communicative a victim is capable of being, the more the evaluation for abuse or neglect depends on scientifically established methods convincing to the public and the law.

Another needed step is to develop a full understanding of how children with and without disabilities are vulnerable to violence in both similar and dissimilar ways,

whether and how the response to their abuse is identical or discriminatory, and how maltreatment affects children with and without disabilities.

The most available systems for responding to abuse of children with disabilities are the states' child protection services. The term "systems" is used advisedly because the variations not only from state to state but even from county to county can make a great difference in the response to child maltreatment.⁵ Little is known comparatively about how the various states train personnel on the topic or respond to abuse to children with disabilities either at home or in out-of-home settings. There are no specialized national standards for responding to violence towards children with disabilities. As for the criminal justice response, in theory various children's justice centers and crime victimization programs for children should respond to the problem. However, there is no systematic comparative data on victim assistance protocols or experience collectively in responding to child maltreatment within this population. Not only children's hospitals but also all hospitals responding to suspected child maltreatment must see children with disabilities who have been targeted for abuse. However, no comprehensive data exists on this issue. There do not appear to be generally available specialized protocols for diagnosing children with and without preexisting disabilities. This is one of several areas in which research is needed.

Programs addressing violence to children with disabilities include some child protection teams, a few treatment programs, and those care facilities with specific approaches to preventing and treating abuse of the children for whom they are entrusted to provide care. Their prevalence and variations in quality of quality assurance programs are unknown.

Research that would clarify understanding of the problem and improve chances for prevention and treatment includes determining how often reports of abuse to children with disabilities are investigated differently from other cases. What preexisting disabilities most confuse medical and non-medical evaluators of suspected maltreatment of children with disabilities? What are the best available approaches to evaluating and treating children with disabilities who might have suffered maltreatment?

Do treatment interventions to address PTSD, transformation of some victims to becoming victimizers, infliction of additional disabilities and maltreatment in homes or out-of-home settings need to be adapted for children with disabilities? To what extent are physically or sexually aggressive behaviors by children with distinctly different types of disability associated with abuse or neglect as contrasted to being intrinsic in some way to their form of disability? To what extent are existing programs for children with disabilities in the schools, protective services and crime victim services providing interventions appropriate for children with disabilities?

Without waiting for all the needed research, advocacy addressed to ensuring that children with disabilities are provided the existing services is needed. Many resources exist today directed at preventing child abuse and neglect, and treatment for maltreated children, while still very limited in its availability, does exist in many communities. Experience shows, however, that without someone to speak for children with disabilities maltreatment will be neither prevented nor treated once it occurs.

Introduction

To begin I wish to acknowledge the teaching and support I've received from Cordelia Robinson, Edward Goldson, Larry Edelman, David Manchester, David Thomas, Steven Rosenberg, April Block, Lynnette Disheroon, Lula and Gretchen Lubcenko, all of whom are associated with the Department of Pediatrics of the School of Medicine at the University of Colorado. Most of these individuals are also associated with either JFK Partners or the Kempe Children's Center, or both. I would also like to thank D. K. Marge and the organizing committee for Preventing and Intervening with Violence against Children and Adults with Disabilities, and the sponsoring Centers for Disease Control and Prevention, U. S. Department of Justice, U.S. Department of Education, and the Paralyzed Veterans of America.

The task of defining child abuse and neglect has remained consistently problematic throughout the modern examination of the problem.⁶ It is common to type the problem as being one of four kinds: physical abuse, sexual abuse, neglect and emotional abuse, but these categories beg the question and definitions vary as a function of the purpose to which they are put: clinical, research, legal, or policy analysis. For the purposes of this paper, I am agreeing with my colleague Ed Goldson who used two definitions in his excellent review of maltreatment and disability.⁷ According to P. L. 93-247 effective in 1974, child maltreatment is "the physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a person who is responsible for the child's welfare under circumstances which indicate harm or threaten harm to the child's health or welfare." Pioneering pediatrician Ray Helfer defined maltreatment as "any interaction or lack of interaction between family members which results in non-accidental harm to the individual's physical and/or developmental states."⁸

The significance of child maltreatment, including maltreatment of children with disabilities, can be measured in many ways. From the advent of mandatory reporting of suspected child abuse in 1963 until the 1990's, confirmed and nationally documented cases of child abuse and neglect rose from zero to nearly 1,000,000 cases annually. From 1992 until 1994 the Federal estimate of confirmed cases based on reports from the States essentially leveled. The last five years of available data [<http://www.acf.dhhs.gov/programs/cb/publications/cm99/cpt2.htm>] showed a drop to some 830,000 confirmed cases by 1999. Included in this number are estimated to be over 1000 deaths annually due to maltreatment, a figure that might be much higher due to problems of misclassification.⁹

Given that there are both large numbers of children who are maltreated and large numbers of children with disabilities, what is the overlap? "What is known about this population of children with disabilities? In 1994 there was a death rate of 7.6 per 10,000 live births attributed to homicide, including child battering. This is the ninth most common cause of infant mortality. One would suspect that many infants with disabilities were included among the dead, although the exact numbers are not available. If one considers maltreatment among the disabled, not including death, the reported incidence of abuse in the disabled population in 1991 was 14% or 35.5/1,000 children with disabilities compared to an incidence of 21.3/1,000 children without disabilities."¹⁰

In his already classic book **Violence and Abuse in the Lives of People with Disabilities**¹¹, Dick Sobsey addresses the issue of whether children with disabilities face greater risks of maltreatment. "While many small studies (often

methodologically weak) have reported the children with disabilities are more frequently abused than other children, inconsistencies in the estimates of the extent of increased risk, along with a few studies that fail to demonstrate a relationship, leave some uncertainty about the nature and the magnitude of the relationship.¹² However, when these studies are considered as a group they provide powerful evidence of a link between the two (Sobsey, 1988).¹³ Sobsey continues: “When definitions of abuse are limited to more severe forms of abuse and multiple victimizations of the same individuals are factored in, their relative risk is probably at least twice as high as the general population. Differences in definition of abuse, reporting rates, contextual variables, and sampling strategies mean that no single figure will ever reliably express differences in risk between people with and without disabilities. Therefore, it has been suggested that the time has come for research to go beyond merely trying to measure the strength of association between disability and abuse, by concentrating future research on determining why the relationship exists (Sobsey, 1988) (cited above). Westcott (1991)¹⁴ points out that regardless of the precise level of risk, we know that significant numbers of individuals with disabilities are abused and that society’s failure to respond to their needs for prevention and intervention must be addressed.”

The consequences of maltreatment are becoming understood. These consequences can include physical injury to the central nervous system, broken bones, damage to internal organs of the abdomen, burns, malnutrition, and neglect of medical care that would prevent death or serious disability. Early studies of physically abused children documented significant neuromotor impairments, including central nervous system damage, as well as physical defects, growth and mental retardation, and serious speech problems.¹⁵ As early as 1983, Diamond and Jaudes reported that of 86 children evaluated 9%(8) of children with cerebral palsy were abused, but also that 9% acquired cerebral palsy from being abused.¹⁶ Over time most clinicians and researchers have taken the position that whatever the physical harms of child maltreatment, there are always associated and sometimes severe emotional and behavioral consequences for the child. Even after physical injuries heal, the less visible harm to children’s emotional and mental functioning with associated behavioral problems can carry severe consequences and prove harder to treat.

One of the more important and studied questions is the relationship between maltreatment and aggressive behavior. The National Research Council summarized this research in 1993. “Physical aggression and antisocial behavior are among the most consistently documented childhood outcomes of physical child abuse. Most studies document physical aggression and antisocial behavior using parent or staff ratings (Aber et al., 1990; Hoffman-Plotkin & Twentyman, 1984; Perry et al., 1983; Salzinger et al., 1984); other measures, such as child stories (Dean et al., 1986); or observational measures across a wide variety of situations, including summer camps and day care settings (Alessandri, 1991; Bousha & Twentyman, 1984; Howes & Eldridge, 1985; Howes & Espinoza, 1985; Kaufman & Cichetti, 1989; Main and George, 1985; Trickett & Kuczynski, 1986; Walker et al., 1989). Some studies indicate that physically abused children show higher levels of aggression than other maltreated children (Hoffman-Plotkin & Twentyman, 1984; Kaufman & Cichetti, 1989) although other studies indicate that neglected children may be more dysfunctional (Rohrbeck & Twentyman, 1986).”¹⁷

It might be expected that aggressive or delinquent and criminal behavior might appear in later life absent effective interventions. Widom's 1989 prospective study found an approximately 50 percent (26 versus 17 percent) increase in arrests for maltreated children versus a large matched control population, although arrests of juveniles for **violent** crimes were not significantly higher (4 versus 3 percent).¹⁸ In a follow-up article she reported that abused or neglected females did appear to be at an increased risk for arrest for violent crimes during adolescence.¹⁹ Lewis has considered the contribution of psychiatric, neurological, psychological, and abuse factors to violence.²⁰ Some of her research suggests that abuse can make a contribution to aggression and violence independent of mental illness, but perhaps most importantly that organic brain syndrome and severe abuse combined create a multiplied risk of extreme violence over the contribution of either risk factor alone.²¹ If early maltreatment can increase the risk of delinquent behavior, including aggression, then theoretically it should be possible to intervene to prevent child abuse and thus decrease the risk of later arrest for children whose risk of abuse was decreased. Olds and his colleagues have reported success of this exact nature, first helping reduce the physical abuse of children in the intervention group by about 80% through home visits by nurses to first time, high risk mothers in a randomized trial conducted in Elmira, New York, in the 1980's.²² In a 15-year follow-up, both the mothers and the children who received visits by nurses to prevent child abuse and to address other health and development risks experienced a significantly lower arrest probability as compared to the random control mothers and children.²³

Given the background of a probable relationship between physical abuse or neglect and an increase in aggressive and/or delinquent behavior by children and adults, what can be suggested from reports concerning persons with disabilities demonstrating these behaviors? A 2000 state audit for disabilities services and "High-Risk Behaviors as Reported State-Wide" documented the incidence of high-risk behaviors among the population of persons with disabilities served by the state. The two highest risk behaviors listed were "Aggressive Behavior (including assault) 229 (75%)" and Aberrant Sexual Behavior (including Pedophilia and Paraphilia) 133 (44%).²⁴ The high-risk behaviors were documented for many of the 306 individuals receiving comprehensive services such as residential, day program, transportation, and other services required to support them in the community. Some individuals exhibited more than one of the observed behaviors. Individuals charged with physically or sexually aggressive crimes raise similar questions about the source of such behaviors. As discussed below under "needed research," better understanding of the degree to which specific disabilities carry intrinsic risks of aggressive behavior versus the degree to which child maltreatment or other life traumas create risks of aggressive behavior is a very important challenge.

In order to frame the issue of physical aggression thoroughly, aggression towards peers, aggression towards adults either in authority or not, and the relationship between aggression and other forms of misconduct all remain to be understood. However, a key issue yet to be adequately explored is whether these behaviors might be prevented to a great extent by protecting children with disabilities from maltreatment.

While not the focus of this paper, certain risks associated with child sexual abuse should be noted. In addition to sexual misconduct²⁵ directed at younger children,

peers, or even adults, children who have been sexually abused can exhibit a number of behaviors that might eventually be linked to earlier sexual abuse or exploitation. The lack of clarity on this issue compared to physical abuse is partly due to inherent methodological issues of definition, ratings of the severity of the abuse, nature of the perpetrator, sampling problems, measurements used for mental health assessments, validation of the sexual abuse, and lack of control groups.²⁶ Notwithstanding methodological challenges to research on the effects of child sexual abuse, it is possible to examine whether the experience of child sexual abuse places children and adolescents with mental retardation at increased risk for sexual offending. McCurry et al²⁷ used a chart review to look at sexual abuse history, various measures of IQ, sexual victimizing, and history of being sexually abused. Sexual victimizing behavior was significantly associated with a history of being victimized for all the subjects, but mean IQ's were significantly lower for those individuals who had histories of problem sexual behaviors. A study of children with and without developmental disabilities who were sexually abused found many significant differences, all but one of them unfavorable to the children with disabilities.²⁸ Children with developmental disabilities who were sexually abused had a poor sense of personal safety, little or no sexual knowledge, were more likely to make inappropriate sexual comments, practiced self-abuse, were unkempt or dirty on a regular basis, and extremely withdrawn, compared to the sexual abuse victims without developmental disabilities. In the study only sexually abused children without disabilities abused alcohol. The authors believe this probably is due to a lack of access for the children with disabilities.

Parenting difficulties with their own children are a risk factor for maltreated children after they grow up. According to Pears and Capaldi²⁹ "Over the past few decades, researchers have found support for the idea that children who experience harsh or abusive parents are likely to become harsh and abusive parents (e.g. Egeland, 1993; Egeland, Jacobvitz, & Sroufe, 1988; Hemenway, Solnick, & Carter, 1994; Hunter & Kilstrom, 1979; Simons, Whitbeck, Conger, & Wu, 1991; Zaidi, Knutson, Y Mehm 1989). However, intergenerational transmission of abusive behavior is by no means a certainty; estimated rates of transmission vary widely from 18% (Hunter & Kilstrom, 1979) to 40% (Egeland, Jacobvitz, & Paptola, 1989). In large part, the differing estimates are because of a number of methodological problems in the literature, including the use of retrospective designs, varying definitions of abuse, and failure to consider third variable explanations." The research by Pears and Capaldi found a 23% direct rate of child abuse by maltreated parents, controlling for many other factors that in turn added to the explanatory model they created.³⁰ One of the most studied aspects of child maltreatment, intergenerational transmission, is supported by many different studies all of which point out that there is not a one-to-one correlation between being abused and becoming abusive, and that many factors in parent and child mediate the eventual outcome.

While much of the picture remains to be filled in regarding the consequences of child maltreatment, there is reason to believe that abuse and neglect create many risks for the victims. These risks include alcohol and other substance abuse problems, self-destructive behavior, depression, suicide attempts, and problems of intimacy and teenage pregnancy.³¹ Very few of these issues have been explored, much more fully explored, for the maltreated population of children with disabilities as they grow up.

Historical Overview

The seminal paper on the battered child syndrome was published in 1962³² and has proven to be a defining marker as well as an important paradigm for addressing human violence. The authors reported that of 300 abused children found through a survey of hospitals and prosecuting attorneys in the U.S., 11% died and 28% suffered permanent disability as a result of the abuse. Within the next four and one-half years all of the American states adopted mandatory child abuse reporting laws, the first in the world.³³ Subsequently, Ray E. Helfer began his partnership with C. Henry Kempe and their contributions have been described by Sobsey as “mobilizing” the public and professionals to address child maltreatment.³⁴ The battered child syndrome provided essential knowledge about the diagnosis and etiology of child abuse. For example, “discrepant history” remains crucial to differentiating inflicted from non-inflicted injury. The notion that parenting, both good and bad, is largely “learned parenting” was introduced in the original paper. In the late 1960’s Kempe and his colleagues began the pioneering study of home visits to prevent physical abuse of children. This model was adapted and successively converted into a standardized protocol for preventive interventions by nurses by David Olds and colleagues.

In 1974, through Public Law 93-247, the Federal government began a limited grants program to encourage more standardized reporting laws across the U.S. The new law also provided competitive small grants for pilot programs and resource centers across the U.S. Some of the early connections between disability and child abuse were strengthened by recipients of these grants, Gerry Solomons of the University of Iowa and Don Kline at Utah State. In a presidential address to the Cerebral Palsy Society, Gerry Solomons spoke on the cross over aspects of cerebral palsy and child abuse. Don Kline worked to draw the special education community’s attention to the problems of maltreatment. In *Violence and Abuse in the Lives of People with Disabilities*, Sobsey’s second chapter uses developments in the area of child abuse to provide the template for most of his discussion of violence and disability. Following a summary history of child protection leading to modern developments, Sobsey’s review establishes that much of the available research has focused on child maltreatment and has been published in the latter third of the twentieth century. The work of the pioneers in examining both child maltreatment and its relationship to developmental disability over the past thirty to forty years is cited throughout this monograph.

It is not entirely understood why formerly violence was not viewed in the context of childhood. It might be that the relative economic, political and personal security offered in the second half of the twentieth century to students of child development and care created conditions permitting examination of pathology in the care of children. Certainly the objectivity and hard to deny evidence of repeated fractures at different stages of healing made visible by radiology was a foundation for the new awareness.³⁵ Few humans enjoy being confronted with problems that are upsetting, make the observer feel incompetent in terms of knowing how to respond, and lacking institutional frameworks for guidance on appropriate responses. The recent “discovery” of the problem also suggests that it was “too close to home” in its wide-spread prevalence and “normalization”.

Once given understanding and belief that the problem is widespread and potentially devastating in its consequences, as well as given initial frameworks for response, efforts to understand the etiology of child abuse and neglect have

increased greatly. Additional early attention was placed on parental factors, including the possibility of mental disturbance or a history of parents themselves receiving inadequate care in their own childhoods, the “intergenerational hypothesis”. Clinicians reported that immediate “triggers” in the child’s behavior, for infants crying, toileting, and feeding, might precipitate abuse. A crisis in the home whether economic, marital, substance abuse, or some other factor, was often found to be present in cases presenting for diagnosis. “Isolation” of a psychological more than a geographical nature has also been supported to some degree as contributing to the ecology of maltreatment.

In the last twenty-five years, models have developed which encompass many different variables. “Although simple models identified key variables associated with child maltreatment – often termed ‘risk factors’ – they did not establish a firm etiology of child maltreatment or specify causal relationships or sequences between the associated variables. Furthermore, results across these studies are often conflicting, and the predictive power of single variables, such as the individual characteristics of the parent, child, or environment alone, is limited. The emerging social interactional models emphasize the importance of viewing child maltreatment in the context of the family, community, and society rather than emphasizing only individual parental psychopathology or individual stressors (Belsky, 1980, 19992; Cicchetti and Carlson, 1989; Garbarino, 1977; Parke and Collmer, 1975; Wolfe, 1991). The phenomenon of child abuse and neglect has thus been moved away from the conception of an individual disorder or psychological disturbance, toward the conception of a symptom of an extreme disturbance of childrearing, often part of a context of other serious family problems, such as poverty, alcoholism, or antisocial behavior (Burgess, 1979; Pelton, 1989; Starr, 1979; Wolfe, 1991). New empirical findings invoking the interaction models suggest that, although studies of abusive and nonabusive parents have not detected important significant differences in terms of personality dimensions, studies of the interactions of abusive and nonabusive family processes have yielded important distinctions, including unrealistic expectations of their children, the tendency to view their own children’s behavior as extremely stressful, and their view of themselves as inadequate or incompetent in the parenting role (Wolfe, 1991).”³⁶ This understanding caused the National Research Council to adopt a “developmental/ecological/transactional model of the etiology of child maltreatment” as the basis for its review of the research literature.³⁷

A number of lessons can be learned from studying the general problem of child abuse and neglect. All children are alike in the vulnerability of their minority, irrespective of any special susceptibility. Children are more easily harmed than adults in general, whether they are victims of violence, sexual impropriety, or neglect. Clearly this must be truer with younger children due to their limitations of physical strength, lack of pure physical size, or capacity to anticipate and respond to danger. For example, studies of training children to prevent sexual abuse show only limited effects, which in turn suggest that attention to identifying and intercepting predation as well as physical attacks, e.g. through parent education, will probably prove more effective.³⁸ All younger children, unlike many adults, require active care giving until able to provide as much self-care as possible. They can die of exposure or starvation as well as abuse, because they can find neither sustenance nor shelter. Nor can they as easily defend themselves by running away for reasons of physical, emotional or educational capacity.

As the history of understanding of the overlap between child maltreatment and disability has unfolded, it is clear that there are many areas in which the comparison of the experience of abused children with and without disabilities can offer greater understanding of what will be needed to address the problem. The general case of child maltreatment connects with children with disabilities in a number of ways. Some children, both with and without disabilities, can be more difficult to care for than other children. Children with disabilities represent an important subset of children who can be particularly challenging for caregivers. Yet study of children with disabilities offers prospects for understanding the broader picture of child maltreatment. "It is often underappreciated that the empirical examination of disability and maltreatment has direct implications for our understanding of abuse and neglect in all children. Most models of maltreatment (e.g. ecological model) acknowledge that certain child characteristics can play a role in maltreatment, particularly in already at-risk families and environments (cf Ammerman, 1991).³⁹ As many children with disabilities exhibit some of these characteristics (e.g. vulnerability, difficult to manage behavior problems), they provide an opportunity to examine and elucidate the contribution of child characteristics in maltreatment in general, and physical abuse in particular. This is illustrated in a study by Ammerman and Parz (1996)⁴⁰, in which negative child characteristics were associated with increased child abuse potential in both mothers and children with and without disabilities."⁴¹

Additional barriers hamper efforts to prevent and intervene concerning violence against children with disabilities. Establishing the etiology of injury can be more difficult when there is more than one possible source of trauma: genetic, preexisting condition or illness, prior inflicted or non-inflicted injury, versus current inflicted injury. The importance of this fact is that multiple explanations are a complicated setting in which to determine "res ipsa loquitur" information or "information that speaks for itself," a key to unlocking child abuse historically. One barrier in diagnosis can be overcome when children can communicate the source of harm they have suffered. Barriers to communication can exist, however, in addition to immaturity. Many of the risk factors discussed to this point were in evidence in a case referred to the Kempe Children's Center for consultation. A nine-year old boy severely affected by cerebral palsy was discovered to have a fracture just above the knee of both legs. The facility and parents were uncertain as to whether his injuries were accidental or not. It was known that he had suffered from decalcification and was particularly vulnerable to fractures. Reviewing the records and accounts of those important his life, we were able to focus attention on a particular paid caregiver charged with preparing him for transportation and conveying him to and from a van. It was clear that this boy could communicate, sometimes in strong terms, his basic likes and dislikes. An examination of the wheel chair used to move him to and from the van showed that metal bars on the wheel chair lined up exactly with the twin fractures he had suffered. Following additional interviews, it turned out that the caretaker in question had been seen "shoving the boy down hard" into the wheel chair once when he was irritated with the boy's behavior.

Another barrier to proper evaluation for inflicted injury is denial or discounting of the possibility of maltreatment by responsible caregivers or professionals. This can occur when injury or additional harm occurs to a child who is viewed by some in society as already "damaged goods". Fortunately, in the situation just described there was a sufficient "index of suspicion" to cause a thorough review of a boy's injuries.

Abuse of children can happen at home or in out of home settings as evidenced by many confirmed reports of abuse. In a series of focus groups held by Larry Edelman of JFK Partners with parents of children with disabilities, two widely different themes emerged. Parents of children with disabilities felt that other people perceived their child as having been maltreated and as a consequence now suffered from disability. Other parents of children with disabilities indicated that whether or not they ever felt “accused,” when they had reason to believe that their children might have been maltreated by someone else, their children’s problems were ignored.

Abuse outside the home has been slower to attract attention. Physical abuse by non-parental caregivers can occur during transportation, at schools, in foster care and in residential settings. For example, Hobbs and Hobbs (1999)⁴² reviewed 158 incidents of physical or sexual abuse to 133 children all of whom were in foster or residential care. Of the 133 children, 12 had learning disabilities. In a case that occurred early in my career a case was referred from a residential facility for infants and toddlers with severe developmental disabilities. A number of children were found to have unexplained fractures, and eventually a nurse was suspected of causing inflicted injuries to approximately 16 small children. The nurse was discharged. The problem of unsafe care facilities has been known and documented for a longer period than modern attention to child maltreatment. While historically adapted as a means of improving the lives of abandoned children, institutional care in the form of foundling homes, orphanages, and almshouses “offered little surcease from death.”⁴³ Progress in this area remains uncertain. For example, the issue of whether ‘reasonable corporal punishment’ should be used to justify inflicting pain on children continues to be an issue in homes and institutions in the United States, as discussed in the next section.

Current Theories, Plans, and Efforts

Perhaps the most important theoretical discussion currently concerns the continuing societal, cultural, professional and scientific debate on corporal punishment and whether it is an acceptable form of teaching or disciplining children with or without disabilities. To the extent that the word “discipline” derives from “disciple” or student, the use of both words teaching and disciplining might appear redundant. No matter the meaning; using “pain to the body” (the literal meaning of “corporal punishment”) as a means of disciplining children remains contentious. How to draw the line between physical abuse and corporal punishment is not, however, generally raised as an issue in extreme cases of injury to children. Instead, whether bruises on a child or other relatively minor injuries resulting from corporal punishment constitute “abuse” or a reasonable form of discipline does continue to raise debate.

A respected sociologist, Murray Straus, has long argued against using corporal punishment to discipline any children marshalling as much evidence as he can to argue his opposition.⁴⁴ Meanwhile, many states have abolished corporal punishment in schools, statutory bans on corporal punishment have been proposed,⁴⁵ and research continues to be conducted on physical punishment, subabusive violence,⁴⁶ and whether punishment of any kind is necessary or unnecessary.⁴⁷ There appears to be some agreement, including from researchers not confirming clear effects on children’s aggression from corporal punishment⁴⁸ that the context of corporal punishment does matter. Among risks of unfair, inconsistent and harsh punishment can be alcoholism, depression⁴⁹ and subsequent

antisocial behavior, both in the near term for younger children⁵⁰ and at least two years later for older children.⁵¹ However, maternal warmth might militate against some bad effects,⁵² and bad effects of moderate spanking might depend on a combination of infrequent reasoning and frequent spanking, which were associated with a dramatic increase in aggression in one study.⁵³

Given lack of clarity about which of many inherited, pregnancy or birth related disabilities could include any predisposition to physical or sexual aggression whatsoever, the issue of corporal punishment to children with disabilities seems especially important. In just the past fifteen years corporal punishment has been justified and upheld in a state supreme court as a substitute for medications for children with disabilities.⁵⁴ Persons with mental retardation are sometimes charged with violent crimes that seem out of character with most persons of similar background. The work of Patterson and his colleagues in decreasing antisocial behaviors of children by improving parental discipline without resort to physical punishment makes this discussion both important and hopeful.⁵⁵

The primary response to identification and reporting of suspected child maltreatment in the United States is by child protection agencies, although police can also be notified. This is true generally whether the suspected abuse occurs in or out of the home, although for some institutional abuse situations the police become the primary responding agency. All fifty states mandate reporting of suspected child maltreatment, although the list of individuals required by law to report varies from state to state. Once a report is received and evaluated, even if confirmed it is unlikely to go to a civil court proceeding and is highly unlikely to go to a criminal court proceeding.

Media accounts and professional lack of clarity contribute to the public's misunderstanding of the different types of legal intervention that occur with respect to violence against children with or without disabilities. The criminal system is designed to punish bad conduct and thereby to deter the bad conduct. Due to laws on confidentiality the public becomes aware primarily of abuse or neglect cases involving failure, either of overintervention (a family feels damaged by a mistaken or disproportionate intervention) or underintervention (a child is killed by abuse or neglect and a failure of an agency to intervene is blamed). Due to sensational cases in which there is prosecution of extreme abuse, many in the public probably feel that the criminal system plays a dominant role in responding to child abuse. Many might be surprised that as few as 4% of cases confirmed by a case worker are prosecuted, and that fewer than 30% of cases confirmed are filed in juvenile or family courts.

One of the problems of the current approach to child maltreatment in the U.S. is the insufficiency of population-based data not only on confirmed reports, but repeated abuse, successful treatment, successful adoptions, and successful long-term reunifications and achievement for children and families once reported. Thus the public's image of the field is more easily shaped by scattered newspaper accounts given the absence of easily accessed accounts of success and failure in preventing or treating violence to children. In contrast, the public is well aware that outbreaks of disease are handled by public health in a "non-accusatory but imperative" process of identification and control of outbreaks. For example, it is fully expected that an outbreak of salmonella in a bottled juice product or an e-coli outbreak from a fast food chain will be investigated and proper orders issued to correct the threat. In a parallel fashion, most are aware that some individuals

are involuntarily treated for mental illness when they represent a direct danger to themselves or others. Again, the person who is mentally ill and for that reason alone dangerous is not “accused” of mental illness but a “non-accusatory but imperative” process of mental health hearings can occur. Imagine for a moment the too common example of an infant with inflicted subdural hematomas, retinal hemorrhages, and upper arm grab marks in a situation where an identifiable abuser cannot be identified. The parallel of other “status adjudications” to the “non-accusatory but imperative” process of adjudicating an infant as a “dependent” child is less recognized. There are no population-based data to allow the systematic tracking of violence to children with disabilities inside and outside of their homes, nor how often investigative, legal, or therapeutic interventions occur. With respect to treatment more specifically, there are a few studies that suggest but only suggest that court-ordered treatment can be more effective than voluntary treatment.⁵⁶ In some reports of successful intervention parents have improved their anger control⁵⁷ or reduced abuse⁵⁸ In other studies children have shown developmental gains and better interactions; however, the literature on treating child abuse and neglect whether directed at caregivers or at child victims is not robust.⁵⁹

There are important services, such as crime victim assistance programs and children’s justice centers that became more prevalent and comprehensive during the 1990’s. Child protection teams began in 1958 and are found throughout the U.S., although not yet required as a condition of Federal child protection funding. Like institutional abuse teams and other special teams for responding to violence to children, they can provide a number of important resources in the evaluation and case planning for abused children.⁶⁰ In general, victim’s rights legislation and programs should be better known and better accessed by the community that works with and cares for children with disabilities.

A few educational efforts to address violence to children with disabilities have begun to appear. One example is the manual titled “Assistance for Special Educators, Law Enforcement, and Child Protective Services in Recognizing and Managing Abuse and Neglect of Children with Disabilities (1999) Commonwealth of Virginia,” which is part of the state’s “The Mandated Reporter Assistance Series.” The 110-page manual is available for \$1.65. Such efforts are not uniform throughout the country.

A Look to the Future: Recommendations for Research and Development

Research is needed in a number of areas. Studies of aggressive/violent behavior etiology in children with disabilities, especially as related to maltreatment or interactions between underlying conditions and maltreatment, should be undertaken systematically. The studies should not be limited by assuming that only aggressive discipline or physical abuse of children leads to aggression in children. Neglect and sexual abuse might also increase the risk of later physical or sexual aggression. Given the work by Dorothy Otnow Lewis and others on the multiplicative effects of severe maltreatment and organic brain dysfunction, much more needs to be done to understand how brain dysfunction of any kind interacts with maltreatment to increase the risk of later antisocial behavior. Included in the research should be considerations of children who, in addition to the influence of other forms of disability or maltreatment, have suffered from substance abuse, such as fetal alcohol syndrome.

Randomized intervention research on reducing physical and sexual aggression in children with different developmental disabilities and dual diagnoses is needed to guide parents, agencies, courts and the public on how investments in prevention and therapy might produce greater safety and development for all concerned.

The degree to which the presence of disability distorts investigations of violence to children should be examined for many different systems charged with responding to abuse of children, including protective services, child caring agencies, police and hospitals. How often are the perceptions of some parents correct, that their children with disabilities are perceived as “damaged goods” so that resources are not expended in thorough evaluation of their suspected abuse? In addition, the degree to which disability might interfere with efforts to prevent child maltreatment should be considered. For example, given that children sometimes are not safe even in hospitals,⁶¹ what additional safeguards are needed to decrease the risk to more vulnerable children? Even the idea that children with disabilities are more at risk than other children deserves additional attention as illustrated by recent research on children with craniofacial anomalies. Wald and Knutson interviewed 42 men ages 22-40 with craniofacial anomalies about their experience with discipline as children. No significant evidence was found of disproportionate harsh discipline, but the men did report higher levels of believing they deserved punishment compared to a normative group of men. The researchers attribute this attitude not to a pathological acceptance of abusive treatment but rather to the respondents’ overall moderately low self-image.⁶²

An essential task for diagnosis is to better understand how the principles of “self-evident” diagnostic information can be extended to children with disabilities when maltreatment is suspected. “Facilitated communication” is an area ripe for exploitation and confusion. Whether it does or does not yet provide a reliable means of diagnosing maltreatment is controversial and places enormous responsibilities on the investigator.⁶³ At the same time, there is a great need for improvements in assessing children with communication limits who might have been maltreated and well-trained individuals have begun to adapt certain techniques to these assessments.⁶⁴

Improved policy, in addition to research, is needed in the areas of accountability and auditing theory when children must be placed, albeit temporary or long term, in the care of anyone other than biological parents. Practices in child caring environments must be constantly monitored, as for example with programs of Total Quality Improvement. There are not yet expectations that constant systems of monitoring and proactively working to prevent maltreatment have been implemented in most out of home care settings.

A related issue is the need to better assess the care giving capacity of volunteer and compensated child caregivers. When the most affected “consumers,” i.e. children with and without disabilities, cannot tell us whether the services they’ve received are acceptable, good or abusive, then the challenge for accountability in other means must be accepted. One key to total quality improvement would be greater confidence that the care giving capacity of individuals volunteering or hired to provide care is adequate or, preferably, excellent.

When transparent communication of children’s experiences cannot be assured, such measures as “base line” physical and mental monitoring might be implemented. Detection of abuse or neglect via specific communication devices, e.g. through computerized medication performance monitoring of compliance to

child-initiated SOS signals remain to be explored as both research and policy issues.

Given the complexity of need and the developing range of available services, education concerning maltreatment of children with disabilities becomes a more obvious need and opportunity. Parents need to know more about the relative risks of exploitation of their children and some of the steps that can be taken to reduce risks. When it is possible that a child has been maltreated, parents, professionals, and institutions must have developed practical protocols that require immediate and appropriate responses to the suspicion. All of the programs that are in a position to evaluate or treat children with disabilities who might have been or are proven to have been maltreated, must be prepared to respond responsibly and effectively.

Among the often-misunderstood aspects of victimization is the need to support the non-offending parents of children who have been abused.⁶⁵ Victims' assistance efforts and appropriate response to children with disabilities and their parents

Taken together, those working with child maltreatment and developmental disability have much to offer each other and the children and families they serve. There are many challenges and many opportunities, particularly in the interaction of these two fields but also with other fields responding to family violence in all its dimensions.

(Endnotes)

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VIOLENCE AGAINST WOMEN WITH DISABILITIES

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Executive Summary

It was only a few years ago that the Center for Research on Women with Disabilities (CROWD) reported shockingly high rates of violence against women with disabilities, rates that were similar to those reported by women without disabilities (Nosek et al., 1997). As we became familiar with a voluminous body of sound research on violence against women, we observed that those studies neglected the element of disability. Since that time, we have witnessed an ever-increasing number of scientific publications reporting on empirical investigations of abuse and violence against women with disabilities. This paper summarizes the literature and works in progress and presents an update on the state of the science on violence against women with disabilities. While efforts have been made to include all relevant information, we acknowledge that the paper emphasizes the work of investigators at the Center for Research on Women with Disabilities where the majority of these studies have been conducted.

Empirical studies have begun to identify the prevalence, vulnerabilities, and health-related consequences of abuse experienced by women with disabilities. Advances have been made regarding the definitions and assessment of disability-related abuse. Information has been compiled and disseminated about resources for resolving abuse. Empirically-based interventions are being developed that are designed to prevent abuse and assist women with disabilities who are currently in abusive situations.

Analysis of abuse in a national survey of 439 women with disabilities and 421 women without disabilities revealed similar rates of abuse; the prevalence of any emotional, physical, or sexual abuse was 62%, the same for both groups (Nosek et al., 1997). When comparing lifelong experiences of abuse, the groups did not differ on age at first onset of abuse, types of abuse, or the woman's relationship to the perpetrators. However, the women with physical disabilities, compared to women without disabilities, reported a significantly greater number of perpetrators and a significantly longer duration of abuse. We identified types of abuse that are specifically related to disability from more than 100 narratives written by women with disabilities in this survey.

To identify women with disabilities who are in abusive situations, CROWD developed and tested the Abuse Assessment Screen – Disability (AAS-D) (McFarlane et al, 2001). This four-item instrument is concise and relatively simple to administer in a clinical or social service setting. Two items were designed to identify disability-related abuse manifesting as 1) denial of medications or access to assistive devices and 2) withholding of essential personal assistance.

Interviews with 31 women with disabilities revealed several factors that may increase their vulnerability to abuse: 1) inability to escape a situation, 2) lack of adaptive equipment, 3) stereotypes of vulnerability, 4) increased risk in

institutional settings, 5) increased exposure to medical settings, and 6) dependence on perpetrators for survival activities (Nosek, 1996).

To clarify risk factors for abuse, we conducted a study of 415 women with disabilities. This study suggested that women with disabilities who are younger, less mobile, have greater depression, and have less social support have a higher likelihood of experiencing physical, sexual, or disability-related abuse within the past year.

CROWD investigators have conducted a recent analysis suggesting that women with physical disabilities may be more vulnerable to experiencing stress if they have experienced abuse in the past year (Hughes, Taylor, Robinson-Whelen, & Nosek, in preparation). Another investigation on depression and women with spinal cord injury indicated that depression levels were greater for participants who reported current abuse compared to women not reporting abuse (Hughes, Swedlund, Petersen, & Nosek, 2001).

Findings from a survey assessing battered women's services for women with disabilities suggested that only a small proportion of disabled women receive such services, that personal assistance services were rarely available, and that the program staff were unlikely to have had disability awareness training.

Safety planning interventions are needed that are designed to meet the specific needs of women with disabilities. CROWD has developed and pilot tested a program addressing the nature of violence, barriers to leaving abusive relationships, and guidelines on developing and implementing a safety plan (Taylor, Hughes, Mastel-Smith, Howland, & Nosek, in preparation, 2002). CROWD also conducted a survey about the responsiveness of rehabilitation service providers to abuse and women with disabilities, concluding that few routinely ask about or discuss abuse with disabled women. Low rates of disclosure of abuse may be a result of mandatory reporting laws wherein women do not want the violence documented in fear of retaliation by the perpetrator. Most states mandate the reporting of abuse of persons with disabilities.

Solving the problem of violence against women with disabilities will require the involvement of segments of the community that have not traditionally been active in efforts to reduce domestic violence. It is essential that networks of communication be established among those working in the battered women's movement, the disability rights movement, disability service organizations, legal defense organizations, law enforcement, religious organizations, and health care. In this way we can expand the awareness and understanding of preventing abuse and the critical importance of removing the barriers that face women with disabilities who are trying to eliminate violence from their lives.

Introduction

We never expected high rates of abuse among women with physical disabilities. Who would have thought that women with disabilities would have a problem with the horrible experiences we see on TV and in the movies, battering, rape, or the threats of such—unheard of, unimaginable. It took only one conversation to put our antenna up. It was 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. In the qualitative interview phase of that study we asked

if the women had ever experienced anything that they would call abusive. Two-thirds of them spoke to us at length about a wide variety of abusive experiences, from long ago in childhood to lifelong, from all the worst we've seen on TV to forms of terror only a woman with a disability could understand. In that study, we heard 55 separate reports of abuse from 25 of the 31 women with disabilities who volunteered for this study. In our final report on that qualitative study and the national survey that followed, we stated "Although there has been a wealth of research on domestic violence and sexual assault against women, with clearly defined variables and strong scientific methodology, it almost never incorporates the element of disability" (p. 18, Nosek, et al., 1997). Now, with the support of federal funding agencies, we have joined with other researchers to change that picture by systematically defining disability-related variables and methodologies (Gilson, DePoy, & Cramer, 2001; Hassounh-Phillips & Curry, 2002; McFarlane et al, 2001; Nosek, Foley, Hughes, & Howland, 2001; Nosek, Howland, & Hughes, 2001; Nosek, Hughes, & Taylor, 2002; Swedlund & Nosek, 2000; Saxton et al, 2001).

We set out to determine what constitutes abuse, how prevalent it is, what differences there might be in the vulnerability of women with disabilities compared to women in general, the health consequences of abuse among disabled women, how available and accessible helping resources are, and interventions that could prevent abuse and assist women with disabilities who are currently in abusive situations. Along the way we discovered some of the challenging issues that come up when investigating abuse among women with disabilities. This paper presents a summary of what we have learned and how it supports, contradicts, or adds to the body of literature on this topic.

Definitional Issues: What Constitutes Abuse

Many different definitions exist for the various types of abuse. Virtually every battered women's program and every state human rights or social services law has its own set of definitions; however, there is no standard or consensus on which best suits the purposes of research. In a study conducted by Nosek et al. (1997) the following definitions were identified: **Emotional abuse** was defined as being threatened, terrorized, severely rejected, isolated, ignored, or verbally attacked (Finkelhor & Korbin, 1988; Claussen & Crittenden, 1991). **Physical abuse** was defined as any form of violence against a woman's body, such as being hit, kicked, restrained, or deprived of food or water (Soeken, McFarlane, Parker & Campbell, 1997). **Sexual abuse** was defined as being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape (Soeken et al., 1997; Cole, 1984).

In analyzing data from this study of women with disabilities, Nosek et al. (1997) certain types of abuse that are specifically related to disability. These fell into two broad categories, 1) variations on common forms of emotional, physical, and sexual abuse that would not be as likely if the woman did not have a disability, and 2) abuse that occurred in a disability-related setting or relationship. Although the nature of the abuse revolves around the dynamics of power and control, the presence of disability or context of a disability-related setting or relationship opens new channels for those dynamics. This study identified that **disability-related emotional abuse** often includes behaviors such as emotional abandonment and rejection, or denial of disability. **Disability-related physical abuse** includes physical restraint or confinement; withholding needed orthotic equipment,

medications, transportation; or refusing to provide assistance with essential daily living needs, such as dressing or getting out of bed. **Disability-related sexual abuse** includes demanding or expecting sexual activity in return for help or taking advantage of physical weakness and inaccessible environment to force sexual activity (Nosek, Foley, Hughes, & Howland, 2001). Many of the incidents of abuse reported during the national study conducted by Nosek et al. (1997) occurred in **medical settings** and were perpetrated by medical professionals. Certain acts are clearly abusive and punishable by law, such as rape by an orderly. Others, however, are not so easily categorized, such as physical touch as part of psychotherapy, stripping for examination, or restraints for patients who are agitated. It is sometimes difficult to draw the line between actions that are sanctioned as medically necessary and actions that in any other context would be considered abusive.

The large majority of persons who have significant functional limitations depend on family for personal assistance, since assistance from outside the family is often expensive and not very reliable. In the event that the person providing the assistance is the perpetrator of abuse, the disabled woman may perceive that this is her only option, that no one else would assist her, and that abuse is the price she must pay for survival.

CROWD researchers (McFarlane et al., 2001) developed a tool for identifying women with disabilities who are in abusive situations, called the Abuse Assessment Screen – Disability (AAS-D). It is concise and relatively simple to administer in a clinical or social service setting. This measure modified the Abuse Assessment Screen (AAS) (Soeken, McFarlane, Parker, & Campbell, 1998), a two-item instrument that evaluates physical and sexual abuse. The modifications to the AAS included the addition of two items focusing on disability-related abuse, including the assessment of being denied (a) medications or access to assistive devices, and (b) personal assistance needed for essential activities of daily living. This instrument was used to screen 511 women with various types of physical disabilities recruited in Houston public and private chronic care clinics. Fifty women screened positive for abuse. The two items from the original AAS identified 40 women who screened positive for abuse; with the addition of the two disability-related items, an additional 10 women were screened positive for abuse.

Historical Review: Issues of Prevalence

Although the prevalence of abuse among women in general has been fairly well documented, only a few studies (Sobsey, Wells, Lucardie, & Mansell, 1995) have examined the prevalence among women with disabilities. The DisAbled Women's Network of Canada (Ridington, 1989) surveyed 245 women with disabilities and found that 40% had experienced abuse; 12% of them had been raped. Perpetrators of the abuse were primarily spouses, including ex-spouses, followed by strangers, parents, service providers, and dates. Less than half these experiences were reported. Ten percent of the women had used shelters or other services, 15% reported that no services were available or they were unsuccessful in their attempts to obtain services, and 55% had not attempted to get services. Sobsey and Doe (1991) conducted a study of 166 persons where 82% were women and 70% persons with intellectual impairments. In 96% of the cases, the perpetrator was known to the victim; 44% of the perpetrators were service providers. Seventy-nine percent of the individuals were victimized more than once. Treatment services were either inadequate or not offered in 73% of the cases. The Ontario

Ministry of Community and Social Services (*Toronto Star*, April 1, 1987) found that more disabled women had been battered as adults compared to women without disabilities.

Nosek et al. (1997) conducted a national survey in which both women with (n=439) and without (n=421) disabilities were asked if they had ever experienced physical, sexual, or emotional abuse. The prevalence of any abuse for women with and without disabilities was 62%, and similar proportion of women with disabilities and without disabilities reported emotional, physical, and sexual abuse. None of these types of abuse was significantly different for women with or without disabilities. Thirteen percent of the women with disabilities had experienced physical or sexual abuse within the past year.

The most frequent perpetrators of emotional and physical abuse among both women with and without disabilities were spouses and live-in partners, followed by parents. Strangers were the most frequent perpetrators of sexual abuse for both groups. Women with disabilities were more likely to experience emotional abuse by attendants, strangers, or health care workers than women without disabilities. Women with disabilities were more likely to experience physical or sexual abuse by attendants. Women with disabilities experienced abuse for significantly longer periods of time than women without disabilities. Findings from this study suggest that a greater number of women with physical disabilities experienced more complex and intense patterns of abuse over their lifetimes than women without disabilities.

Current Theories, Plans, and Efforts

The question of whether or not women with disabilities are at greater risk for abuse compared to women in general is currently under serious debate. It is often said that women with disabilities are at substantially higher risk. Early studies report that the rate of abuse among women with disabilities ranges from 31% to 83%, or double to quadruple the rate found among women in general (Ontario Ministry of Community and Social Services, 1987; Sobsey, 1988, 1994; Sobsey, et al., 1995; Sobsey & Doe, 1991; Cusitar, 1994; Stimpson and Best, 1991; Ridington, 1989). On close examination, however, one finds methodological limitations including the lack of comparison groups, samples combining both genders, samples combining children and adults, and lack of distinction between past and current abuse (Nosek, Howland, & Hughes, 2001).

Several empirical studies have been conducted regarding the vulnerability for abuse among women in general. A review of research on abuse among women identified many risk factors but only less education, unemployment, and a history of child emotional/verbal victimization demonstrated moderate to strong effect across the studies (Schumacher et al., 2001). The combined cultural devaluation of women and persons with disabilities is may increased the vulnerability for abuse (Belsky, 1980), often compounded by age-related devaluation (Kreigsmann & Bregman, 1985). Overprotection and internalized societal expectations are other contributors. Womendez and Schneiderman (1991) characterized the experience of women with disabilities as having fewer opportunities to learn sexual likes and dislikes and to set pleasing boundaries. Women with disabilities often perceive celibacy or violent sexual encounters as their only choices, believing no loving person would be attracted to them. Various explanations have been considered for increased vulnerability to victimization among persons with disabilities such as increased dependency on others for care; perceptions of

powerlessness; less risk of discovery; difficulty being believed; less education about sexuality; being isolated, and physical helplessness (Andrews and Veronen, 1993).

Economic dependence is another factor that may increase the vulnerability of women to abuse. Farmer and Tiefenthaler (1997) propose that improved economic opportunities for women may decrease violence in abusive relationships. Participation in the labor market is 33% for women with disabilities, dropping to 13% for full-time work, compared with 69% for men with disabilities (Danek, 1992; U.S. Bureau of the Census, 1989). Even college-educated women with disabilities are less successful in obtaining employment than college-educated men with disabilities or non-college educated women without disabilities (Fine & Asch, 1988, p. 11; Bowe, 1984).

Many women with disabilities rely upon others for personal assistance. This may increase their susceptibility to abusive actions that may not be considered abusive to women in general. This disability-related abuse can be dangerous to women with activity limitations (Curry, Hassouneh-Phillips, & Johnston-Silverberg, 2001; Saxton et al. 2001). Saxton et al. (2001) conducted focus groups and interviews with women with disabilities to identify definitions of personal assistance, the barriers women face in dealing with abuse, and women's strategies for preventing or stopping the abuse. Their study identified the following themes: boundary confusion; expanded forms of abuse due to relying on others; complexities of relying upon family and friends as providers; barriers preventing women from getting help; and suggestions for preventing or stopping abuse.

An analysis of qualitative data identified several disability-related vulnerability factors: inability to escape a situation due to architectural inaccessibility, lack of adaptive equipment, stereotypes of vulnerability, increased risk in institutional settings, increased exposure to medical settings, and dependence on perpetrators for survival activities. (Nosek, Foley, Hughes, & Howland, 2001).

No known studies on abuse among women with disabilities have empirically explored risk factors, in the strict sense of the word. Nosek, Taylor, Hughes, and Taylor (2002) analyzed data from a sample of women with disabilities (n = 415) and found that women with disabilities who are younger, more educated, less mobile, more socially isolated, and who have higher levels of depression are more likely to have experienced abuse within the past year. Due to the cross-sectional design of this study, however, it could not be determined if these variables were the cause or effect of abuse. Longitudinal studies should be conducted to identify factors that constitute an actual risk for abuse.

Health Consequences of Abuse

Women suffer adverse health consequences due to battering and other forms of abuse. As a result, domestic violence has been identified as a significant public health problem in the U.S. (U.S. Department of Health and Human Services, 2000). Although there has been a great deal of research on violence against women, few studies have investigated abuse and women with disabilities, despite that fact that 21% of the women in the United States have disability-related work limitations (Jans & Stoddard, 1999). The risk for abuse, effects of abuse on health, and barriers to seeking help for disabled women remain largely undocumented (Hassouneh-Phillips & Curry, 2002).

The literature on women in general indicates that domestic violence and other forms of abuse result in homicide (Kellerman & Mercy, 1992), suicide (Browne & Finkelhor, 1986), disability (Murphy, 1993), emotional problems (Ratican, 1992), medical complaints (Faria & Belohlavek, 1984; Courtois & Watts, 1982; Cunningham, Pearce, & Pearce, 1988), drug and alcohol abuse (Faria & Belohlavek, 1984; Finkelhor et al., 1986; Briere & Zaidi, 1989), and sexual dysfunction (Ratican, 1992). Sexual abuse survivors may experience depression, (Browne & Finkelhor, 1986) chronic anxiety and tension (Briere & Runtz, 1988), anxiety attacks and phobias, as well as sleep and appetite disturbance. Many survivors also have more medical complaints including pelvic pain (Cunningham, Pearce, & Pearce, 1988) as well as headaches, backaches, skin disorders, and genitourinary problems (Faria & Belohlavek, 1984; Courtois & Watts, 1982). It is important to note that many of these conditions are already more prevalent as secondary conditions among women with disabilities, making it more likely for physicians to attribute causation to the disability and to fail to pursue abuse as a possible cause. Survivors also experience exaggerated feelings of guilt and shame, negatively affecting their self-esteem and enhancing feelings of worthlessness (Bradshaw, 1989). These feelings often result in poor body image, leading to obesity or eating disorders (Courtois & Watts, 1982; Gordy, 1983; Kearney-Cooke, 1988). Self-destructive behavior, self mutilation, drug abuse, and alcoholism occur more frequently than among non-abused women (Faria & Belohlavek, 1984; Finkelhor et al., 1986; Briere & Zaidi, 1989). A history of abuse may have serious effects on a woman's relationship and sexuality issues, engendering feelings of passivity, powerlessness, lack of trust, and isolation. Left untreated, sexual abuse may lead to serious psychological sequelae (Ratican, 1992).

In our study of 511 women recruited through public and private chronic care clinics, we investigated the relation of abuse to depression and stress. To date, we have examined the characteristics of depression among women with spinal cord injury (SCI) (n=64) (Hughes, Swedlund, Petersen, & Nosek, 2001); a similar analyses is in progress that uses the entire sample of women (n=415) who responded to the depression and stress items (Hughes, Swedlund, Taylor, and Nosek, in preparation). Like all women with disabilities, women with SCI may be at an elevated risk for depression due to the double jeopardy of being female and having a disability. Depression is at least twice as common among women compared to men (McGrath, Keita, Strickland & Russo, 1990), and persons with physical disabilities appear to be at greater risk for depression than the general population (Turner & Noh, 1988). The mean depression score, as measured by the Center for Epidemiologic Studies- Depression (CES-D) (Radloff, 1977) was 20.9 (SD = 12.6), and 59.4% of the sample scored at a level indicating the likelihood of depression using the recommended cut-off score of 16. Higher CES-D scores were significantly associated with lower levels of education and income, unemployment, greater perceived stress, less social support, lower vitality, greater social isolation, less mobility, and greater pain. Depression scores were higher for the nine women reporting current abuse compared to women not reporting abuse. These findings suggest that psychosocial factors, especially stress and social isolation, appeared to play a more potent role in the depression of women with SCI than disability-related or demographic factors. finding that offers an important contribution to the relevant literature.

The findings from an investigation by Hughes, Taylor, Robinson-Whelen, & Nosek (in preparation) on the relation of abuse and other correlates of perceived stress suggest that women with physical disabilities may be more vulnerable to greater levels of stress if they are younger, have less income, have less mobility, and have a greater need for assistance with both activities of daily living and instrumental activities of daily living. Social support, high levels of pain, and abuse experienced in the past year are associated with greater levels of stress.

Best Practices in Abuse Prevention and Intervention

The development of resources and improvement of services for victims of abuse are key aspects of abuse intervention for women with disabilities (Nosek, Howland, & Young, 1997; Swedlund & Nosek, 2000). The National Domestic Violence Hotline keeps a database of battered women's programs throughout the country, with indications of their architectural accessibility and the availability of interpreter services. Although the hotline is equipped with telecommunication devices for persons who are deaf, it is rarely used. The National Coalition Against Domestic Violence issued a manual that gives specific guidelines for battered women's programs on implementing accessibility modifications according to the requirements of the Americans with Disabilities Act and increasing sensitivity and responsiveness among program staff to the needs of abused women with disabilities (National Coalition Against Domestic Violence, 1996). Little is known about the ability of battered women's programs to meet the needs of a woman with disabilities who is living in an abusive environment. Considering the multitude of barriers reported by women with disabilities who seek services from battered women's programs, we developed a two-tiered survey process to collect data related to the issues identified in telephone interviews with a panel of abuse experts and to describe service delivery to women with disabilities by battered women's programs. The first-level questionnaire was mailed to 2,703 programs nationwide that deliver abuse-related services; 2200 came from the National Domestic Violence Hotline database of programs self-reporting wheelchair accessibility. To be eligible to receive the second survey, programs had to have provided abuse services of any type to at least one woman with a disability during 1997. The second survey was mailed to 494 eligible programs, and 234 completed surveys were returned. The responding programs reported a wide range of percentages for the portion of women they served who had various types of disabilities.

The most commonly reported service provided to women with disabilities was accessible shelter or referral to an accessible safe house or hotel room. In the second survey, Seventy percent said they would offer a woman with a disability their wheelchair accessible emergency shelter, 64% said they would refer her to a shelter in a nearby town that has space available, and 56% said they would contact law enforcement to remove the perpetrator from her home, 10% would tell her they would call back when space becomes available and 52% would suggest that she stay with a friend or relative.

Some abuse programs provided wheelchair-accessible transportation to the shelter and individual and/or group counseling. Nearly half provided an interpreter for hearing impaired women, and one-third offered TDD communication. Less than half presented workshops or other training on recognizing potentially violent situations. Approximately one-third offered safety plan information modified for use by women with disabilities, and disability awareness training for program staff. The service least likely to be offered was personal care attendant services.

Only 12% of the abuse programs offered education to law enforcement personnel about disability-related abuse. Program staff were unlikely to have had disability awareness training, and only a few had a program staff member specifically assigned to provide services to women with disabilities. The most serious problems confronting providers of abuse prevention and intervention services were insufficient specialized funding for disability-related services, inadequate respite services for family caregivers in the community, and lack of accessible transportation to attend the abuse program. The most effective outreach services for making women with disabilities aware of the abuse services offered by a program was community presentations and training. These findings suggest that only a very small proportion of women with disabilities who are being abused, particularly those with physical or sensory disabilities, receive services from battered women's programs.

CROWD's survey of 41 ILCs demonstrates how this collaboration can successfully address some of the unique barriers encountered by women with disabilities when accessing community abuse programs (Swedlund & Nosek, 2000). Independent living centers may help identify women with disabilities experiencing abuse and help these women access community services. ILCs can also help domestic violence shelters and sexual assault programs improve their accessibility and responsiveness to women with disabilities. They have also provided personal assistants to women in shelters or who need respite care because of an abusive care provider. Many of the ILCs in the survey address abuse issues through their individual and group counseling services. ILCs also train abuse intervention program personnel on needs of women with disabilities. In turn, abuse program staff train ILC staff on abuse issues.

As a result of these studies, we (CROWD) produced three directories: a directory of battered women's programs that highlighted the services they offer to women with disabilities (Howland, 1999), a guide for domestic abuse programs (Myers, 1999), and a guide for independent living centers working with abuse survivors (Myers, 1999).

Safety planning interventions are needed that are designed to meet the specific needs of women with disabilities. The Center for Research on Women with Disabilities has developed and pilot tested a program addressing the nature of abuse and the cycle of violence, barriers to leaving abusive relationships, and specific guidelines on developing and implementing a safety plan (Taylor, Hughes, Mastel-Smith, Howland, & Nosek, in preparation, 2002). This instructional program will soon be made available on videotape, and plans are underway to apply for funding to test the efficacy of this intervention via a randomized controlled trial.

Training of Service Providers and Clinicians

We conducted a survey to assess the ability of rehabilitation service providers to identify women in abusive situations and to refer them to appropriate community resources (Young et al., in press). As primary service providers to women with disabilities living in the community, rehabilitation counselors and independent living specialists have the opportunity to recognize abusive situations and to initiate the interventions that can bring about change. Our survey was completed by 535 rehabilitation service providers; 13% were employed in a state vocational rehabilitation agency, 57% in other vocational rehabilitation settings such as the office of private rehabilitation providers or hospitals, and 30% in independent

living centers. Three-quarters of the respondents indicated that women with disabilities are vulnerable to family violence and sexual assault, and felt that they could recognize the signs of abuse in their clients; 91% said they knew where to refer them in the community; and almost all indicated that abuse of a woman with a disability interferes with her vocational or independent living goals. Although 80% of respondents believed it was within their job responsibilities to deal with abuse issues of their clients, only 19% reported that they routinely ask about family violence and other types of abuse. The survey asked, "Of the women with disabilities you served in the past year, approximately what percent discussed with you their experiences of abuse, such as domestic violence, sexual assault, or abuse by caregivers?" The mean was 12% (S.D.= 21%; range 0-100%). Twenty percent of the respondents indicated that no women with disabilities had discussed abuse experiences with them; 76% of them reported 10% or less. It was no surprise that this question was significantly correlated ($r=.43$) with whether or not the respondent routinely asked about abuse experiences. In other words, those who asked about abuse were more likely to find it. Ninety percent of the respondents indicated a need for more information about abuse prevention and intervention strategies for women with disabilities and 78% would attend a training session on these topics (Young et al., accepted).

Legal Issues

In the process of designing our study to examine abuse as a secondary condition by recruiting women from chronic care clinics, we were introduced to the dilemma of state mandatory reporting laws. The recruitment phase of that study was delayed due to the consideration of the State of Texas mandatory reporting law for abuse of persons who are elderly or disabled (1995). We believed that being required to inform the women that we would report abuse would potentially increase the number of false negatives. Due to the sensitive nature of the study and its inherent risk of retaliatory violence, the safety of each participating woman was paramount in our procedures. Consultations were conducted with various legal and compliance offices. An attorney from Adult Protective Services interpreted the mandatory reporting requirement to apply to persons with disabilities who are not legally competent or who cannot speak for themselves (i.e., cannot seek help without assistance). This attorney interpreted the word "disabled" in the relevant code to mean a person who has both severe physical and cognitive impairments. However, our concern related to the confidentiality of disclosure of current abuse by a research participant who has a physical disability but who does not have a severe cognitive impairment. Our informed consent form, therefore, stated that we were required to report the current abuse of persons with disabilities who could not speak for themselves. We were granted by our Institutional Review Board a waiver of the regulatory requirement of written documentation of consent in order that the research could be practically executed. To assure that the woman's participation in the study could never be discovered by the perpetrator or through subpoena of records, we conducted the screenings anonymously and thus did not schedule appointments or document the woman's name in other ways. Our procedures included asking that each participant to mark an 'x' on the signature line, and having two members of the research staff sign that they obtained consent. Although this procedure was cumbersome and staff-intensive, we determined that it was a protective alternative to the possibility that the identity of the woman could ever be revealed or reported without her expressed consent.

A Look to the Future: Recommendations for Research and Development

It has been established that emotional, physical, and sexual abuse of women with disabilities is a problem of crisis proportions. This population faces some unique vulnerabilities to abuse beyond those experienced by women in general. There are two key factors that may contribute to the tendency for women with disabilities to be subjected to abuse for significantly longer periods of time than most women. First is the perceived and real lack of options for escape and for receiving assistance from programs for battered women and other abuse relief services. Second is the general inability of disability-related service providers to identify women who are in abusive situations and refer them appropriately.

We offer the following recommendations for increasing the accessibility and availability of battered women's services for women with disabilities. a) Modify shelters for battered women so they are fully accessible, including barrier-free access to sleeping rooms and common areas, architectural features that comply with the Americans with Disabilities Act, visual and auditory alarm systems, available interpreters, and TTYs for telephone communication; b) ensure that all services offered by battered women's programs are fully accessible and integrated for women with disabilities, including hot lines, individual counseling, and support groups; c) provide or refer legal assistance for obtaining restraining orders and managing court systems; d) keep statistics on the number of women with disabilities who call crisis hot lines or use other program services; e) assist and encourage police in recording disability status in their crime reports, as well as encouraging adoption of a separate category for perpetrators who are caregivers; f) train staff on how to communicate with persons who have hearing, cognitive, speech, or psychiatric impairments. Staff should understand environmental barriers faced by women with physical and sensory disabilities when offering advice or referrals for obtaining shelter; g) have on hand an extensive network of community referrals and contact numbers, including volunteers or other community resources for obtaining personal assistance; h) offer training to disability-related service providers, including independent living centers and churches, on recognizing the symptoms of abuse and the characteristics of potential batterers. Service providers should be familiar with and able to refer to resources for battered women in their community.

We offer the following recommendations for social service providers who may have contact with women with disabilities, such as rehabilitation counselors, social workers, ministers, case managers, and persons working in medical settings; a) seek out information about how to recognize the signs and symptoms of abuse. Suggest that in-service training on this topic be offered for staff of your organization; b) incorporate into your work the practice of talking with clients directly and privately about the suspected abuse. Assess the degree of danger they may be experiencing. For situations of extreme danger, contact the police and Adult Protective Services; c) help clients develop a safety plan that they could follow to escape their situation should it become life threatening; d) document in the client's record your observations and discussions about abuse; e) plan for follow-up to discuss the abusive situation; f) give clients information on resources (e.g., phone numbers for battered women's program) that could help them deal with abuse.

For expansion of the knowledge base on abuse among women with disabilities, we offer researchers, research educators, and research funding agencies the following recommendations:

- 1) Disseminate to researchers and research educators information about the most effective techniques and designs for investigations on abuse among women with disabilities, particularly concerning: a) using definitions that distinguish emotional, physical, sexual, and disability-related abuse; b) using population-based sampling methodologies; c) securing informed consent; d) maintaining confidentiality; e) installing safety measures to protect study participants and the project staff from retaliation by the perpetrator; f) taking special efforts to ensure the inclusion of women with disabilities from minority backgrounds; g) using appropriate, validated, disability-sensitive screening instruments; h) recruiting homogenous disability samples and comparison groups; i) understanding the legal requirements for reporting abuse; j) incorporating in research designs variables that assess vulnerability for abuse; k) implementing abuse studies in clinical settings; and l) including formative and summative evaluations in outcome studies of abuse interventions.
- 2) Develop and test interventions to prevent violence against women with disabilities and assist those who are currently in abusive situation to remove violence from their lives. Special attention should be given to: a) involving women with disabilities who have experienced abuse at all stages; b) conducting a thorough review of the literature early in the research planning process to identify interventions that have been developed and tested for abused women; c) consulting individuals active in local battered women's programs for effective strategies; d) obtaining information from programs that are exemplary in assisting women with disabilities in abusive situations; CROWD has a list of such programs; e) assessing the effectiveness of an intervention with formative and summative evaluation procedures; f) establishing as outcomes related to beliefs, knowledge about abuse, self-efficacy, safety behaviors, contacts with resources, and, ultimately, reduction in abusive incidents and the risk for such incidents; g) including variables and conducting analyses to determine the extent to which demographic characteristics, disability factors, psychosocial factors, and environmental factors affect improvements in the outcomes of interest.
- 3) Use qualitative research techniques to examine abuse issues about which little is known, plus participant satisfaction with interventions and the perceived usefulness of the intervention materials and methods among program staff.
- 4) In developing abuse interventions, give special consideration to the functional limitations associated with disability, the possibility of a lower literacy rate, and cultural appropriateness.
- 5) Conduct randomized controlled trials of abuse interventions for women with disabilities with multi-year follow up to determine effectiveness in improving outcomes and to identify risk factors for abuse.
- 6) Replicate the designs of exemplary studies in the literature for investigations of abuse among women with visual and hearing impairments, cognitive impairments, learning disabilities, and mental illness.

Solving the problem of violence against women with disabilities will require the involvement of segments of the community that have not traditionally been active

in efforts to reduce domestic violence. It is essential that networks of communication be established among those working in the battered women's movement, the disability rights movement, disability service organizations, legal defense organizations, law enforcement, religious organizations, and health care. In this way we can expand the awareness and understanding of preventing abuse and the critical importance of removing the barriers that face women with disabilities who are trying to eliminate violence from their lives.

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INTERVENTION APPROACHES FOR ADULTS WITH DISABILITIES WHO BECOME VICTIMS OF VIOLENCE

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Introduction

Statement of the Problem

In some circles, the existence of the problem of abuse of adults with disabilities is very well acknowledged, while in others it is rarely if ever mentioned. While child abuse has become very well recognized, and accepted among the lay population as a serious social and criminal problem, neither elder abuse nor abuse of children and adults with disabilities has gained widespread attention. This is true as well among those responsible for responding to the abuse, including protective services agencies, victim services, mental health services for survivors, police, district attorneys, investigators and judges. Thus, when cases come to their attention, their lack of exposure to information, training, procedures or policies for working with individuals with disabilities denies them the ability to effectively and sensitively respond.

Thus, several issues related to “what is the problem” arise. One is this first issue, that the problem has not gained widespread **recognition**. The second is that there is very **little research** to demonstrate and substantiate the fact that this is a problem. Thirdly, the research that has been conducted and reveals high levels of abuse among people with disabilities is **poorly distributed**. Fourth, the individuals who should be aware of this information, those who provide generic victim services for the public, are **not made aware** of the prevalence of violence against individuals with disabilities nor how to effectively and sensitively respond when cases come across their desk. And, finally, such lack of service and response may have an effect upon victims who, believing that they will not receive effective or sensitive response within these agencies, **choose not to report** the abuse they have experienced.

So, taken one by one, let’s look at these issues.

The problem of recognition. First of all, people with disabilities have not gained widespread public recognition as full participants in the community. ADA, The Americans with Disabilities Act, passed in 1990, brought a great deal of attention momentarily to issues of disability, but focused the public’s attention on structural barriers, not on service barriers, nor on the fact that people with disabilities need every type of service that people who do not have disabilities need. Thus, court houses, police stations, rape crisis centers, and all buildings that provide services to the public should be physically accessible, and they are not. Professionals and other staff who have disabilities are still not considered when agencies do reconstruction or renovation projects. All construction and renovations for programs that will serve the public, should initially be done according to ANSI universal accessibility standards. In addition, all services provided within those buildings should be accessible, and they are not

So, with this lack of general recognition, it is no surprise that when victims of crime who have disabilities are discussed, this fact about the life of a person with a disability comes as a shock to many professionals. It shouldn’t, but it does...this

will be addressed further in another section of this paper, under “thinking”. In this portion of the paper, I will simply say that to not know that people with disabilities are victims of crime is a result of failure to think, as well as failure to have been exposed to this explicit information. In a recent discussion with the Violence Against Women’s Office, a discussion arose in which one individual suggested that in service delivery for folks with disabilities, we had to encourage people to “think outside the box”, referring to thinking that was restricted within the confines of “traditional” practice. I countered this vigorously by pointing out that most crime victim responders were not even thinking IN the box...in fact, they are not even thinking!

The job is to get people to actually think. I gave two examples of why I believe that people are not actually thinking. One was that in a recent conversation with a woman who has been a special education teacher for over twenty years, she stated that in all her years she never thought that any of her students could have been a victim of child abuse. This conversation occurred in 1999. C. Henry Kempe published his seminal work on “Battered Child Syndrome” in 1962, and by 1964 child abuse had become a national disgrace. Since there was a 37 year gap, I questioned the teacher about her knowledge of child abuse. She stated that she was aware of child abuse, but did not think it had anything to do with her students. She could not explain why, nor had it ever occurred to her. Now that she was thinking about it, she saw the possibility. She began to see that “students” are children, and children experience child abuse.

The second example is that of a police officer in Southern California with whom I had an opportunity to converse regarding the completion of the mandatory Suspected Child Abuse Report Form used in California. On the form, in box 13, there is a question: “Does the victim have a developmental disability?”, and the boxes underneath for yes or no response. I asked him if he routinely completes this question on the form. A police officer for 18 years, he said he’d never noticed the question, nor had he ever responded to it. Obviously, then, there is no requirement for all forms to be completed, I learned. Then, I asked why he thought the question was there. He was unable to figure that out, but agreed that it might be important for data collection. I asked if he were to fill it out in the positive, what would cause him to check the “Yes” box...he said “if the child were crippled or blind or something”. I asked if he knew the legal definition of “developmental disability”. He did not. I asked if he thought there might be a legal definition, he said he was unsure. I asked why he thought, since he did not know this, why he had never inquired about box 13, that is, what does it mean, how should it be completed, why is it important, etc. Again, he said he’d just never paid much attention. I learned so much from him. I learned mostly that his lack of curiosity about completing a mandatory form was permitted, and that such lack of curiosity and educated response is a key to the next steps needed for data collection! I also learned that such thinking is not the norm, but probably the exception, and that for purposes of expanding effective and sensitive services for any population, the key to getting folks to think about it still needs to be found.

The second problem is that of the small amount of research that has been conducted on abuse in the lives of adults with disabilities. In terms of children with disabilities, only two research studies of national significance have been conducted and completed. The first was conducted by Westat under the auspices of NCAAN and published in 1991. This demonstrated that overall, children with

disabilities are abused at rates 1.7 times that of generic children. The second was conducted by Boystown Hospital, with results published in 2001, demonstrating an overall rate of children with disabilities being abuse victims at 3.4 times the rate of generic children. All prior studies, when compiled, show an increased rate of abuse as being somewhere in the range of 4-10 times that of generic children. Thus, with certainty at this point, one can say that conservatively speaking, children with disabilities are abused at about 3.5 times the rate of generic children. There have not been such extensive studies completed on adults with disabilities. One could look at the smaller studies that have been conducted, to arrive at some estimates of incidence. One also could take the child abuse rates and apply them as an estimate for adults with disabilities, then citing differences among adults that would either increase or decrease their vulnerability. Without an extensive study, however, we look to the studies that exist which study specific subpopulations of adults with disabilities.

For example, Dr. Margaret Nosek at the Baylor College program has a multi-year research program underway to research maltreatment among women with disabilities at the Center for Research on Women with Disabilities (CROWD) through a grant from the U.S. National Institutes of Health. Although final prevalence numbers are not yet available, preliminary reports are that from among the 31 women interviewed in the first phase of this the study, twenty-five reported being abused in some way. Of 55 separate abusive experiences, 15 were reported as sexual abuse, 17 were physical (nonsexual) abuse, and 23 were emotional abuse. Nosek (1996). Analyses of these data (Young, Nosek, Howland, Chanpong, & Rintala, 1997) showed that abuse prevalence (emotional, physical and sexual abuse) was the same (62%) for women with and without disabilities. There were no significant differences between percentages of women with and without disabilities who reported experiencing emotional abuse (52% versus 48%), physical abuse (36% in both groups), or sexual abuse (40% versus 37%).

In another study, the Disabled Women's Network of Canada (Ridington, 1989) surveyed 245 women with disabilities and found that 40% had experienced abuse; 12% had been raped. Perpetrators of the abuse were primarily spouses and ex-spouses (37%) and strangers (28%), followed by parents (15%), service providers (10%), and dates (7%). Less than half these were reported. 15% reported that no services were available or they were unsuccessful in their attempts to obtain services. Fifty-five percent had not tried to get services.

Sobsey and Doe (1991) conducted a study of 166 abuse cases handled by the University of Alberta's Sexual Abuse and Disability Project. The sample was 82% women and 70% persons with intellectual impairments, and covered people from 18 months to 57 years of age. In 96% of the cases, the perpetrator was known to the victim; 44% of the perpetrators were service providers. Seventy-nine percent of the individuals were victimized more than once. Treatment services were either inadequate or not offered in 73% of the cases.

Obviously, an extensive and well developed research project is needed to discover the extent and type of abuse experienced by adults with all types of disabilities. In addition we need to know factors that relate to such abuse such as identification of the perpetrators, location, types of abuse, among other data.

The third issue has to do with the fact that the research that has been conducted and reveals high levels of abuse among adults with disabilities is poorly distributed. I believe that this is a function of the first problem, that of recognition

among those providing crime response services as well as those providing disability related services. If information about the epidemic level of crime against adults with disabilities were made part of public knowledge as well as in the training for service providers, there may be more of a call for such information in regular and special training programs.

The fourth issue is related and is that the professionals responsible for effective and sensitive management of cases of abuse of adults with disabilities are not made aware of either the existence of the problem, its extent, or what to do to prepare themselves to provide excellence in service delivery. Failing in this regard, is a key element in the basic components of the service system.

And, finally, the fifth issue in this circle of difficulties, many adults with disabilities choose not to report the abuse they have experienced, due to a perception or knowledge that their situation will not be handled effectively or sensitively. Others do not report due to a lack of information that such acts can and should be reported and yet others do not know that they can get help to make the abuse stop.

The question becomes one of how and where to intervene in this seeming cycle of inadequate response to a critical problem of epidemic proportions. This will be addressed specifically in this paper.

Definitions

In beginning this paper, I resorted to the dictionary to clarify the word “intervention”, which is defined below. I learned that the usage of the word had formed in my mind a completely distinct definition, that is, to “proactively provide services to another to ameliorate suffering, accelerate healing, and cause normal institutional responses to occur which, without such intervention, would be unlikely to self generate”. Following are the definitions found in the dictionary¹:
in·ter·vene, in·ter·vened, in·ter·ven·ing, in·ter·venes

- To come, appear, or lie between two things: You can't see the lake from there because the house intervenes.
- To come or occur between two periods or points of time: A year intervened between the two dynasties.
- To occur as an extraneous or unplanned circumstance: He would have his degree by now if his laziness hadn't intervened.
- To involve oneself in a situation so as to alter or hinder an action or development: “Every gardener faces choices about how and how much to intervene in nature's processes” (Dora Galitzki).

To interfere, usually through force or threat of force, in the affairs of another nation.

In my definition, my “world” is revealed. Over the past more than 25 years working with and for individuals with disabilities who have become victims of crimes, I have learned that the systems that have been developed and designed to help crime victims, often deny their services to crime victims who have disabilities, or they provide these services differently. Frequently, the individuals working for police departments, sheriff departments, district attorneys offices and even judges, arbitrarily change “the rules” when working with individuals with disabilities. What does this mean? It means that the “rules” may or may not be applied, when it comes to issues of disability.

For purposes of this article, intervention will refer to “any assistance that is provided to a crime victim that will help in the healing or adjudication of the case”. Thus, this includes assistance in reporting the abuse, all activities in response to the report including interviewing, investigation, adjudication issues, mental health treatment, legal assistance and advocacy.

In making a differentiation between intervention and prevention, it is important to review the definition of prevention. “Prevention”, a public health term, utilizes an approach of primary (informing the entire public), secondary (informing and treating persons potentially impacted by the problem) and tertiary (treating those who have acquired the problem) prevention methods. Thus, for the problem of abuse among adults with disabilities, both secondary and tertiary prevention foci are included, that is, informing and treating individuals who are likely to be victims or responders, and then providing specific services when needed. It has been my experience that the term “prevention” is used to imply that violence can be eliminated, so it is important to clarify the public health definition for purposes of this discussion.

And finally, regarding disability, for purposes of this paper, all types of disability are included in this discussion as well as all types of abuse. Without belaboring the point, all disabilities acknowledged through the Americans with Disabilities Act, and all abuses recognized in the Elder & Vulnerable Adult Abuse statutes, as well as all codified crimes, are included as violations for the purposes of this paper. Further, disabilities that are acquired as a result of the abuse or neglect are considered part and parcel of this discussion.

I would like to acknowledge the importance of the contributions of many individuals to the body of knowledge that is now available. These individuals include the researchers, practitioners, philosophers, victims and their families, who have shared their thinking and experience and together are building toward a universal awareness of the importance and scope of this problem, and the possibility for improved, effective and sensitive response when crimes occur.

History of the Problem and Current Efforts Toward Resolution

Over the past 30 years since I have been involved in issues of abuse and children and adults with disabilities, there have been many years where little interest in attending to the needs of these crime victims on the part of the response system. It has been an uphill battle getting the interest of protective services, police, investigators, and juries and judges, towards a serious endeavor for justice for these victims. Approximately 15 years ago, for example, I met with the Training Director of the Los Angeles County Department of Children and Family Services, described the epidemic of abuse of children with disabilities, confirmed that their workers do not receive training in this area, and offered to provide this training to the Department. She said, “Nora, I just can’t get excited about this issue.” No training was ever provided, to my knowledge.

In 1962, the efforts of C. Henry Kempe brought to indisputable attention the problem of physical abuse of children. Following this, national recognition of the problem resulted in the development of abuse and neglect protective services programs for children throughout the nation, as well as the development of public and private agencies dedicated to developing effective and sensitive response to these cases. Yet, to date, the National Center for the Prevention of Child Abuse (now Prevent Child Abuse America) which produces a national report on child abuse in America, has not included children with disabilities in its data collection

nor in its report. In the 80's recognition of elder abuse began to grow, and in response laws against elder abuse and agencies to respond to elder abuse began to proliferate. Although at least 20 years behind child abuse, elder abuse has begun to have national recognition as a substantial societal problem, but does not enjoy the same level of concern that is displayed for child victims of abuse. And, lagging behind are the vulnerable adults, now recognized in law and included in the elder abuse services and legislation in most states, but little recognized nationally either by the general public or the crime victim response system. Yet, having dependent adult (or vulnerable adult) abuse laws is a major step forward. Reporting is not mandatory, yet, and efforts for mandatory reporting are fraught with controversy, as those wishing to protect vulnerable people also want to protect the dignity and independence that are so important. When to intervene, how to intervene are issues ethicists and practitioners are struggling to resolve. Adding to that, budgets are nowhere near sufficient to respond to the abuse cases that are reported.

It is well understood and documented that when a problem is named, and that name is repeated often, recognition increases. One problem is that "elder & vulnerable adult abuse" is frequently referred to as "elder abuse", with the identification of "vulnerable adults" left out....when this occurs, the whole population is forgotten. Literally. In December 2001 there was an Elder Abuse Summit that was a landmark event. Did it include issues of vulnerable adults? In the reports of the event, there are references to the inclusion of issues of vulnerable adults, but the recommendations, report titles, and references only name elder abuse. Thus, the problems of adults with disabilities as crime victims, disappear from the "mental landscape" with the failure to "call out" the name of the problem.

Around the country, individual states and entities within states have taken it upon themselves to produce research, programs and law enforcement strategies to assure improved response to adult crime victims with disabilities. The institutionalization of these efforts is critical to their continuation. In the past, some great programs have begun, but ended when a particular individual left the agency or program. Or, grant funded programs are unable to locate and secure funding to continue their excellent work.

In 1997 a survey (see Appendix) was conducted to determine what state-level activities, if any, had been conducted to address issues of abuse among individuals with developmental disabilities. Of the 50 states surveyed, 44 responded. The Surveys were sent to the State Departments on Developmental Disabilities. The Survey asks only two questions:

1. Has your State held an Inter-Departmental meeting to address issues of abuse of children and adults with disabilities, and
2. Do you believe that your State currently provides adequate interviewing, investigation, prosecution and intervention services to children and adults with severe disabilities?

Additional comments were solicited. If the State had developed a written report as a result of their Inter-Departmental collaborations, the report was solicited. Of the 44 States responding, 11 had held such a meeting. Of these, 2 were for adults only, 1 for children only.

Of the States which had never had a meeting, 3 answered that they are currently planning a meeting. Of the 11 States that had held meetings they were held by these dates & States:

- 1990 Connecticut
- 1993 New York
- 1995 Arizona
- 1996 Georgia, Louisiana, Michigan, Vermont, Virginia
- 1997 Kansas, New Hampshire
- ? (New Mexico and Rhode Island did not provide dates)

This represents growing interest among the states, yet comparatively few States in the nation had moved forward at the State level at that time. The full Survey report was published in “Community Services Reporter” of the National Association of State Directors of Developmental Disabilities Services.

The Survey was conducted in preparation for California’s 1st Think Tank at the State Level on issues of Abuse and Disability. A report of this Think Tank (request from author) provides the Action Plan that was designed at that meeting in October of 1997, by the State Departments in California with responsibility for crime and abuse victims who have disability. This Action Plan provides a road map that can be used by other states, to design and implement a step by step plan to assure excellence in service to crime victims with disabilities. This body met again in February 2001 when funding became available to implement the plan, to determine which were the best “first steps” to take, and to review the Plan to see what had been accomplished in the interim. Interestingly, no new items were added, as the Action Plan was seen as an adequate approach to the problems.

Based in California, there have been 8 National Conferences on Abuse of Children and Adults with Disabilities, beginning in 1986, with the 8th National Conference held in February 2002. Over 400 people attended representing more than 20 professional endeavors. The multidisciplinary audience was said to be one of the most important aspects of the Conference, according to the evaluations. This was an exciting event, as people came from all over the nation representing programs and progress in many areas of responding to abuse.

Other efforts towards resolution include Vertical Prosecution Units that have been established across the nation. These allow for specialized “teams” that handle such cases from the time of the report, through investigation, interviewing, prosecution and adjudication. It has been found that having expertise throughout the process, as well as a working team that handles only these cases, has increased not only the effectiveness at each juncture of the process, but added sensitivity during the process for the victim and the family, and increased filing of cases has been possible with better outcomes in adjudication.

In addition, the development and implementation of Multi Disciplinary Teams in various counties or other regional designation, has greatly enhanced the process both for the victims and the responders. The State of California developed a “Minimum Standards Protocol” (See appendix) for responding to cases of Child Abuse. This Protocol calls for a multidisciplinary approach, and it includes provisions for addressing the needs of children with disabilities. This Protocol could be adopted and used throughout the country for addressing the needs of adults with disabilities, as the model is to provide minimum standards in response, while developing the actual protocol individually in each locale, so that the locale’s peculiarities are taken into consideration and all parties can “sign on” as willing partners and participants, largely through the “ownership” that is developed when all parties are working together on putting their protocol onto

paper. The Protocol must be signed by the participants, that is the District Attorney, Law Enforcement and Protective Services agencies, at a minimum, who are involved in all abuse cases.

The Root of the Problem

Beyond these practical responses, however, there is something much more important. This is the next subject to be addressed here.

It does not seem, on the face of things, that whether or not someone has a disability should make any difference whatsoever, in the community response to the crime. But it makes all the difference in the world. Why? Because the fact of having a disability, or acquiring a disability as a result of the crime, causes a change in attitude in the responder. This change in attitude is based in overt and covert teaching conducted in our society about people with disabilities. One cannot...shall I say should not...entertain a serious discussion on the topic of crime victimization and people with disabilities, without a serious discussion of the attitudes that underlie all interventions, or failures to intervene.

This is not to say that having certain types of disability cause an individual to think or behave in ways that differ from “the norm”. It is to say that such a difference calls into action a set or series of negative attitudes, myths and stereotypes, into the mind of the responder. These attitudes cause any one of three responses: (1) failure to provide services offered to crime victims who do not have disabilities, (2) providing lesser services to the crime victim with a disability, or (3) providing CRAZY services! (For a full discussion on attitudes & myths vis a vis forensic interviewing, see, “Interviewing Skills to Use with Abuse Victims who Have Developmental Disabilities”, NCEA, Baladerian 1998)

The first of these is failure to provide services offered to all crime victims. Examples abound, but basically include a failure to interview the victim. There have been many reports that when the responder discovered that the victim has a disability, the victim was not interviewed. Excuses for this behavior include that the responder did not think the victim could talk, could provide an adequate response (if asked), felt that the victim’s style of communication could not be believed, felt that the victim’s disability precluded the ability to tell what had happened, precluded the ability to tell the truth, precluded the ability to understand the responder’s role, assured that whatever the victim might say would be a lie or fabrication, among other assumptions. These are the main excuses given by responders for failing to interview the victim. Instead of interviewing the victim, the responder may conduct an interview with those the victim lives with (family, careproviders) either in front of the victim or without the victim’s knowledge. It is important to note that these individuals may be the perpetrator, or accomplice of the perpetrator. And finally, responders have simply refused to enter into any report taking once the fact of the disability has been revealed.

The second of these is providing lesser services. This has been revealed in providing cursory interviews to a crime victim, resulting in quick assessments that there is no substantiation of the allegation, and the case is closed. No support or response services are discussed or offered. Another of these is in therapy, by providing “green” interns without any training or with minimal training in assault or victimology or traumatology, and without training or preparation for working with victims with disabilities. One of the very big problems here is that the interns are “rotated” out of work with their clients after a 6 month period of time, to work with a different population, leaving the clients then with “rotating” therapists each

six months, all “green” both to the issues and the victim. The second issue in this regard is that the victim may be offered a “one size fits all” program, such as 6 weeks of individual therapy followed by 6 weeks of group therapy. Group therapy is not the best “fit” for everyone, nor is the timing of its introduction the same for everyone. Such programs, then are considered “less than”, as they fail to consider the individual and possibly special needs of the victim with a disability.

And, finally, providing “crazy” services. This can and has occurred at every point along the response continuum. What this means is that if there were no disability present, those involved would likely never think of the same response, and also would never implement it if it came to mind. Here is one example. At this point in time, the concept of “forensic interviewing” has taken hold, and it is fairly well recognized that there are standards for conducting interviews when sexual assault has occurred. In a recent forensic interview with a woman with a developmental disability, a sheriff deputy and his male partner went together to the woman’s house to conduct the interview. They asked if she had a teddy bear or other favorite stuffed animal that she would like to hold during the interview. She replied in the affirmative, and was told she could go get it for the interview, which she did. Subsequently, this teddy bear was used by the sheriffs as a “model” or “anatomically detailed doll”, and she was asked to demonstrate the sexual assault she had experienced, by using her favorite stuffed animal. She thus was forced to sully the teddy bear, impairing the “comfort” that was supposed to be the purpose of having the bear there. This was one of many “crazy” errors, but only two described here. The second was when one of the deputies, seated directly in front of the victim, spread his legs open and, pointing at his genital area with his index finger said, “what to you call this”? I believe that such behavior is not only unprofessional, rude and crude, it is not a technique taught in forensic interviewing, but is “crazy”! To what was he referring? His crotch? His finger? His genitals? His pants? I guess we are lucky he did not remove his own clothing to show what he meant, and after an unsuccessful response from the victim (she had replied, “a finger”????), he apparently gave up on that strategy. If the client had instead been a 24 year old rape victim from a GHB drug experience, I do not believe that he would have done the same things. The question becomes, why does the fact that the victim has a disability allow a professional’s thinking to go awry, and why does the professional allow his behavior to follow? There was never any apology to the victim or her family after a complaint about this was lodged.

In order to provide effective services, we must be aware of these pitfalls, attitudinal errors, and beliefs in myths and stereotypes that, unchallenged, drive our behavior. Most of us are aware of the fun made of errors made by English speakers who yell at non-English speakers in the mistaken attempt to get them to understand...yet when analyzed, anyone knows that yelling in one language does not cause understanding in another! Yet, errors made with people with disabilities are not so well recognized or easily corrected. In order for a “normal” intervention to occur, each responder must make a personal assessment, and a personal commitment, to uncover and correct erroneous beliefs and wrong attitudes. The deadly combination of (1) belief in stereotypes (2) failure to examine one’s personal beliefs, and (3) failure to be pro-active in recognizing one’s lack of information & seeking to remedy this lack, have resulted in not only actions that can be described as resulting from “crazy” thinking, but also, cause damage to the crime victim, the case, and the general information about such cases.

Acquiring and Using Effective and Sensitive Intervention Skills

Thus, when discussing issues of intervention and people with disabilities, **two facts** must be affirmed. **One**, intervention skills and tactics have been extensively researched and resulted in training programs across the nation, providing for a foundation from which professionals work in providing excellence in intervention to generic crime victims. And, **two**, in addressing intervention for people with disabilities, we are adding to skills already developed and experience already in place, for those who will be providing services to crime victims with disabilities. No new wheels need to be invented.

Three factors are needed to add to their skills, to help them effectively and sensitively respond when the crime victim has a disability: (1) **information** about how a disability changes or adds to the services needed by that victim, (2) **a personal recognition** of the critical impact socially engendered disability-negative attitudes can and do negatively impact services delivery, and (3) to **always question** the factual basis of decisions made, to be assured that they are made from a foundation of fact not assumption or other thinking error. When the professional has become (more) aware of these factors, that s/he is then individually empowered and equipped to provide excellence in service.

For any individual, agency or organization whose obligation and/or mission it is to provide services to crime victims, the above 3 approaches should be discussed upon entry into the program, and frequently among staff, with an effort to ensure that there is not a “return to the norm”, the natural slant, away from the training and review of negative attitudes or assumptions that can so easily take over.

The first issue has to do with information about disabilities, and how a particular disability or how that particular disability effects that particular crime victim. For each new case, new information will probably need to be discovered. Of course, generalities about disabilities can be functional at the very beginning, but additional effort is required for excellence in providing effective and sensitive service. For example, once one learns that the fact of having cerebral palsy does not necessarily negatively impact intellectual ability, is a generalization one may wish to keep in mind. In fact, for any difficulty that may exist regarding speech production or language issues, it is critically important to know that the individual most likely does not have any intellectual impairment. Our societal marriage of appearance to ability and verbal communication to intellectual function needs to be ... divorced! There are many great examples of this among celebrities (Stephen Hawking, Christopher Reeve), yet in daily life with non celebs, this remains true. These errors have also resulted for deaf children in being placed for their entire school careers in schools for children with mental retardation. Thus, one may wish to take a position of “assuming normal function” in intervening at the beginning, prior to learning about the individual’s actual disability and it’s impact on the person. All the while, considering the impact of the assault upon the victim’s normal functioning. For example, I have worked with people who have become electively mute following an attack, whose intellectual ability then can only be determined through discovery with those familiar with the victim prior to the attack. As a forensic interviewer as well as a psychotherapist, I work from the position of information, not assumption, that the current behavior match some myth I have from years prior. Thus, although personally I have met many people over my 30ish years in this field, I continue to meet people with conditions I need to research.

The second issue is that of making a personal inventory of myths, thoughts, stereotypes, and assumptions that come into play when working with an individual with a disability. It is like a little voice inside that says things you “would never think” or you believe is not representative of you, but yet there it is. Welcome these thoughts, bring them to the surface for examination and reworking. If suppressed or ignored, they may maintain the power to influence or even manage your conduct in the intervention. By bringing them to the surface for internal review or even better, discussion with your peers, some of the sources of these negative thoughts can be identified, and they can be replaced by reality based thoughts.

The third issue is that of always (well, frequently) questioning the source of information you have or that is provided to you. Asking how a person learned a certain piece of information (all deaf kids can’t dream in color, for example...a myth!), can stimulate discussion, can lead to new information for everyone, or burst another myth or stereotype someone acquired in the fifth grade but never acknowledged intellectually. This is so important, that it cannot be overemphasized or repeated too frequently. The bumper sticker, “Question Authority” is a good one. Here’s an example. A woman with Down Syndrome had been sexually assaulted. Following the attack, her behavior changed, and she began to exhibit sexualized behavior, reminiscent of the attack. Her psychiatrist explained to the group home staff that such behavior was “a normal developmental stage” for women with Down Syndrome in her age group (17-25), and that a behavior modification plan should be developed to extinguish this (normal) sexualized conduct. The group home director, not knowing any better, believed the psychiatrist’s explanation. Had she questioned it, she would have learned that this is blatantly false, probably something the psychiatrist made up as he did not know how to explain the behavior. She may have learned that such conduct is typical in a psychological sense of responding to the attack, and re-enacting it to have some control over the attack. It would have been a good idea for the psychiatrist to question his own assumption, to explore responses to sexual assault in general and in individuals with Down Syndrome. This would have saved the victim from 15 years of nightmares, insomnia, re-enactments, and insidious behavior modification interventions that did not address the problem. After 15 years, the group home “gave up” and took her to a psychotherapist skilled, trained and experienced in working with such cases. Following treatment, the negative symptoms disappeared, the victim and group home staff reported a significant improvement in the client’s behavior, mood, abilities and energy.

I hope that these 3 factors, and the examples given regarding their importance, can be adopted into all agencies that provide intervention services for crime victims.

Recommendations

To further improve intervention in cases of crimes against individuals with disabilities, I suggest the following recommendations be implemented:

1. Each State to follow the “California Model”, of creating a State-Director level Think Tank to design an Action Plan. In addition to the plan, there should be discussion of how to fund implementation of the Plan. The Plan, as in California, can be designed in a one day facilitated meeting. Recommendations for acquiring funding, or sharing resources, should be part of the discussion, but should not interfere with the development of the plan. Follow up meetings of subcommittees should be scheduled on the same day. An annual reconvening of the Think Tank is recommended

2. Each State may want to conduct surveys of various agencies to determine specific needs for assuring that effective and sensitive services are being delivered to crime victims with disabilities.
3. States may wish to develop Vertical Prosecution Units in at least each appropriate jurisdiction, to assure best practices.
4. Counties may wish to adopt California's Minimum Standards Protocol for effective and sensitive intervention with all child and adult crime victims, and assuring excellence for those with disabilities.
5. A level of academic and skills for working with crime victims with disabilities should be instituted, among all agencies providing protective and law enforcement responses to crime victims, as well as other victim services agencies and mental health service providers.
6. In addition, issues of managing such cases during prosecution need to be discussed in terms of properly building the case, documenting, memorializing, and handling the case during a court procedure
7. Failure to apply serious penalties upon conviction of perpetrators continues a pattern of "allowing" perpetrators of crimes against those who are undervalued to get away with the crime. This not only encourages perpetrators to seek out victims for whom they are unlikely to serve a sentence or a serious sentence, but the word gets out, and experienced perpetrators teach untrained perpetrators the tricks to avoiding prosecution and/or lengthy sentences. This is another area that requires serious review and reform.
8. Standards for psychological treatment and psychiatric treatment should be developed across the nation, to assure that proper and effective treatment is being offered. Special information, skills and training should be required when working with individuals with disabilities. (The example of the California State Victims of Crime Program in developing a Standards of Treatment Guidelines Manual, 2001)
9. There should be some agreement on "who wins" when crime victims with developmental disabilities are attacked at the workshop or day program. At the present time, the "norm" is for the "rights of the perpetrator" to continue to work. I believe that the "rights" of the victim to continue to work at a place in which she has been comfortable and where she has a social circle should supercede those of the perpetrator. If the perpetrator will be at a location in which the victim has normal routine activities perpetrator should be moved to another program. If the perpetrator is staff, he should be charged with the crime and fired. The parent/guardian should not disallow the client to return if she wishes. If the victim wishes to go to a new program her wish should be honored.
10. Victim's Assistance Programs provide funding for psychological counseling for crime victims in every state. Generic utilization statistics show that approximately 10% of crime victims ever request psychological assistance through this program. It may be that potential mental health clients are never informed of this option by the law enforcement office with whom they have their case. It should be the responsibility of the LEA and protective services staff to inform each crime victim of this program. Access to the program is through local non-profit or county or city governmental agencies. The Victims Assistance Programs may also wish to advertise their services to disability services agencies, to assure that staff are aware (secondary prevention) of this program when needed.

11. Data is needed in all areas of this problem. Specialized services for victims with disabilities, or generic services that include individuals with disabilities may be provided by any of the following, yet there is no data on either the presence of a program or utilization at: Rape Treatment Centers, National Advocacy Centers, government sponsored child abuse counseling programs, or government sponsored domestic violence programs. It would be good for them to be asked to provide such information to a central data bank.
12. Shelters for battered women with disabilities are needed. Although most receive governmental funding, the funding agency does not require compliance with ADA (Americans with Disabilities Act) to receive funding. This falls under the category, "If you don't have to do it, don't". While compliance is not demanded, it is unlikely that things will change. There currently are no surveys that document the number or percentage of shelters that are in compliance with ADA. Funding agencies should require full compliance with ADA prior to receiving a grant. For those programs already in operation, they should be given a time limit to achieve compliance or risk losing their funding. They can be referred to programs that can assist with information on grants and low-cost/ no-cost compliance measures. There should be AN END DATE of the government continuing to give funds to programs not in compliance with ADA.
13. Community services such as informational brochures, flyers, programs, advertisements, PSA's (public service announcements) lectures and presentations are outreach activities in which most agencies engage and should specifically state that their programs are for individuals with disabilities, include individuals with disabilities in their illustrations, and create a "tag line" stating that the agency is fully accessible. Thus, individuals with disabilities are likely to think that the agency has services for them.
14. It is recommended that agencies to go to service delivery organizations or agencies that serve children and adults with disabilities, further increasing the possibility that people with disabilities will be aware of or contact the agency for assistance.
15. Risk Reduction Training Programs rather than "prevention programs" are needed. These should focus on the agency providing services to the individual. For programs addressing individuals with disabilities, the program should be simple, easy to do, oft repeated, a program that involves others, and is effective. (See PODER by Baladerian)
16. Adults with a disability, as well as their families and care providers should be provided information about abuse and criminal victimization. The curriculum should be adapted to the particular needs of the community and the audience. There are a number of curricula available, and most agencies use a variety of curricula to modify into one that works for them. It is best if the curriculum includes at minimum: A protocol for planned repeated presentations; pre/post testing to evaluate effectiveness of learning; the inclusion of an IRP (Individualized Response Plan); feedback from the community and program participants; a measure of effectiveness, and endorsement from local officials. A brochure should be developed about this problem and distributed to those with a disability, those who have acquired a disability, and all disability related service agencies.

Summary

The exposure to violence of individuals with disabilities is extraordinarily high, yet disclosure, reporting and adequate response by the legal and therapy communities is less than for the generic population. Increased information about the seriousness not to mention existence of this as an epidemic, needs to be made. Public officials who can authorize funding for programs that are ear-marked for individuals with disabilities should be encouraged to do so.

With the current wave of interest, it is hoped that this is a permanent change rather than a fad that will soon disappear. A great many people have been working in their own communities doing what they can with meager funding and support of the community. If this can change into wide support and excellent ongoing funding, the experience of individuals with disabilities who become crime victims will change radically. Further, if educational risk reduction programs are instituted, it is possible that families and individuals can recognize and report assaults better. It is possible that those responsible for intervening when assaults occur against individuals with disabilities can greatly improve their skills and resources. And finally, with funding of programs, there is potential for the interest of mental health practitioners to grow so that communities can serve all members of the public, not just those who do not have disabilities.

Research is an additional effort that is needed to support requests for funding for programs. As indicated above, there are many areas where our knowledge is lacking in response to crime victimization. While this information is needed, at the same time action must be taken now to effectively and sensitively respond to the crime victims currently in need of services.

If the recommendations contained within this article are implemented, the legal and mental health service delivery systems can effectively serve crime victims with disabilities.

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Appendix

STATE OF CALIFORNIA

GRAY DAVIS, Governor

GOVERNOR'S OFFICE OF CRIMINAL JUSTICE PLANNING

1130 K STREET, SUITE 300

SACRAMENTO, CA 95814

(916) 323-7449

CALIFORNIA CHILDREN'S JUSTICE (CJA) TASK FORCE

MINIMUM STANDARD PROTOCOL FOR THE INVESTIGATION OF CHILD ABUSE AND NEGLECT

1. Every county should have an interagency protocol agreement for the investigation of child abuse and neglect developed and agreed upon (signed) by the directors of the following core agencies:

- * District Attorney
- * Law Enforcement (Sheriff and Chief of Police)
- * Child Protective Services or equivalent agency administering child welfare
- * Public Health
- * Tribal Council Representatives

This protocol agreement may include but is not limited to the following additional entities:

- * School districts
- * Probation departments
- * Courts
- * County counsel
- * Clergy
- * Regional centers
- * Mental health
- * Counsel for children
- * CASA (court appointed special advocates)
- * Ancillary law enforcement agencies (such as the federal government and the military)
- * Victim - Witness programs
- * Child Abuse Councils
- * Hospitals/ medical examiners

2. Protocols should include the following:

- * Mission goal and mission statement
- * Written standards and procedures
- * Procedure for periodic review by all agencies involved
- * Procedure for dissemination to all parties involved
- * Procedure for training about the protocol

- * Recognition of the need for ongoing training procedures for professionals involved in the investigation of child abuse
3. Protocols should address all children, including children with special needs, suspected of being abused or neglected in the following situations:
 - * Intra-family or in-home
 - * Out-of-home (e.g., daycare, group homes, public or private schools, foster care, licensed facilities)
 - * Perpetration by stranger
 - * Siblings of a child abuse fatality victim
 - * Homes with domestic violence
 4. Protocols must address a “cascade” or sequence of responses that takes into account the emotional and physical well-being of the child victim.
 - * Initial response following a referral should be coordinated among first responders (i.e., CPS and law enforcement) to reduce redundant interview with or questions to the child. Specifically, the protocol should outline the procedures by which first responders share information with each other.
 - * Investigative procedures for forensic evidence gathering
 - * Reporting procedures (Child Abuse Central Index) and cross-reporting procedures (OCJP forms).
 - * Minimum standards for levels of professional competency
 - * Knowledge of legal authority
 - * Procedures for sharing information with all the parties involved in the investigation
 - * Procedures for getting information about the child victim back to reporters.
 - * Procedures for transporting a child: Who takes the child where, and under what conditions. In addition, procedures for transporting family members if the need arises.
 - * Procedures to ensure that a child with special needs receives prescribed medication or has special equipment, such as a wheelchair.

Procedures must also include the following considerations for forensic evidentiary interviews and medical exams:

 - * Qualification of personnel conducting the interview or exam.
 - * Location of the interview or exam.
 - * Procedures for documentation.
 - * Guidelines for deciding which agency budget will cover the cost of the exam or interview.
 - * Definition of criteria under which a child qualifies for an exam or interview.
 5. The Protocol should address the following issues:
 - * Procedures for denial of entry for any of the responders to a referral for child abuse or neglect.
 - * Procedures for obtaining necessary consent for medical exams and forensic interviews.

- * Procedures for sharing of information among mandated reporters, first respondents, professionals, follow-up investigations.
 - * Procedures for sharing information among professional child abuse investigators that address issues of confidentiality. (Legal confidentiality is narrower than often assumed.)
 - * Procedures for providing information about protective orders, prior history criminal background check, court actions, and placement orders.
 - * Procedures for emergency situations or professional judgment that allow for deviation from the protocol.
6. The protocol must explain how the interagency protocol for child abuse investigation interfaces with or acknowledges the protocols of individual agencies involved and must include procedures for resolving any conflicts among those protocols.

¹ Online Dictionary, dictionary.com

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APPENDIX G:
REMARKS BY INVITED SPEAKERS

**Victims of Crime and Disabilities:
The Criminal Justice System and Victim Assistance Response**

John W. Gillis, Director
Office for Victims of Crime, U.S. Department of Justice

Violence Prevention: The CDC Role

John R. Lutzker, Ph.D., Chief
Prevention Development and Evaluation Branch
Division of Violence Prevention/NCIPC
Centers for Disease Control and Prevention/DHHS

**Preventing and Intervening in Violence Against Children and
Adults with Disabilities: The Role of NIDRR**

Steven J. Tingus, M.S., C. Phil., Director
National Institute on Disability and Rehabilitation Research,
U.S. Department of Education

**OSEP's Involvement in Issues Related to Violence Against
Children with Disabilities**

Stephanie Lee, Director
Office of Special Education Programs
U.S. Department of Education

**Violence Against Persons with Disabilities:
Who are the Most Vulnerable?**

Sylvia Walker, Ed.D., Director
Center for Access to Rehabilitation and
Empowerment Opportunities
Howard University

VICTIMS OF CRIME WITH DISABILITIES: THE CRIMINAL JUSTICE SYSTEM AND VICTIM ASSISTANCE RESPONSE

**Remarks by John W. Gillis, Director
Office for Victims of Crime**

Thank you and good morning. It's a pleasure and an honor to join you here today in addressing the needs of crime victims with disabilities and the critical role that you as advocates, service providers, researchers, educators, victims, and family members of victims play in identifying and addressing those needs.

Like many of you, I came to work in the victims' field in the wake of personal tragedy. While I was serving as an officer with the Los Angeles Police Department, my daughter, Lourana, was murdered as part of a gang buy-in. Her murderer moved up the gang hierarchy by killing the daughter of a cop. Since that day, I have worked not just for victims' basic legal rights, but for full acknowledgment and respect for all victims' dignity and humanity. I am continuing that fight as Director of the Office for Victims of Crime, where I have been charged with helping to guide federal policy on the issues of victims' rights and services.

During my seven months there, I have had the opportunity to hear from many victims and service providers about the good work being done in the field and about their ideas for improving OVC's response to victims' needs. Indeed, it is my understanding that many of you in the audience today have worked closely with OVC on numerous projects in the past four years to promote a greater awareness and understanding of disability and victim issues, and to share information on your innovative work to assist crime victims. For that I thank you. For our new friends today, including the organizers of the conference - SUNY Upstate Medical University, the CDC and other Federal partners, it's a privilege to join with you to support this conference. This gathering today and tomorrow represents another step forward in stopping the victimization of children and adults with disabilities and ensuring that all crime victims, including victims with disabilities, can participate fully in the criminal justice system and receive the services to which they are entitled.

For those of you who are not familiar with OVC, I'd like to give you a little background on our office and the crime victims' field. OVC is a federal agency, and is part of the Department of Justice. Our Office was formally established in 1988 through an amendment to the Victims of Crime Act of 1984, or VOCA, as we call it. OVC's mission has always been to advocate on behalf of crime victims and to lead the way in changing the attitudes, policies, and practices that have prevented them from participating fully in the justice system. OVC also administers the Crime Victims' Fund, which provides formula and discretionary grant funding to support direct services and compensation for victims. We provide training for those who work with victims, support projects that enhance victims' rights and services, and we strive to increase public awareness of victims needs and issues. In the past two years, over 1 billion dollars has been distributed by OVC to states and organizations to directly benefit crime victims. Yet not a single tax dollar goes into the Crime Victims' Fund. Instead, fines and penalties paid by Federal criminal offenders make up the fund. I consider the Fund to be the Federal

Government's best-kept secret: it holds offenders accountable for their criminal actions and supports the services that are critical to victims. OVC is one of the major sponsors of this conference, and it is the Crime Victims Fund that made this support possible. I have only touched the surface about our work at OVC, but I invite you to visit the OVC resource table to get more information about OVC, victims issues, and the training and technical assistance resources available from OVC to assist you with the life-line services that you provide to victims every day.

As many of you may know, the crime victims' field itself is a young one. On April 16th as part of the federal commemoration of National Crime Victims' Rights Week, I had the honor of joining President Bush and Attorney General Ashcroft in recognizing eight organizations and individuals for their outstanding service to crime victims. Among the honorees was the nation's first full-scale victim assistance program-Aid for Victims of Crime in St. Louis-which opened its doors thirty years ago, effectively launching the victims' movement. This anniversary carries no small significance and we are right to celebrate it. After all, we can now talk about the thousands of domestic violence shelters, rape crisis centers, homicide support groups and other programs across the country that reach out to crime victims everyday.

But as successful as the crime victims movement has been, we understand fully that many victims have been left behind. Every year, thousands of individuals who are victimized never receive the support and interventions that are needed to stop the violence perpetrated against them. They never receive the services and support that would help them participate in the criminal justice system and to begin the process of physical and emotional healing.

This is particularly problematic when we talk about crime and individuals with disabilities. While there is not yet a comprehensive, national survey that definitively captures the nature and scope of violence perpetrated against people with disabilities, the studies that have been done are consistent and horrifying, and clearly indicate that a person with a severe physical or cognitive disability is much more likely to be victimized than someone without a disability. They are much more likely to be repeatedly victimized, frequently at the hands of the very people who have been charged with their care.

We also know very little about the number of people who acquire a disability as a result of the crime committed against them. We know even less about whether the supports and services available to them are appropriate and adequate. I know that there are numerous researchers participating in this conference, and your ongoing and future work, in this area will help us better understand the nature, scope and dynamics of violence perpetrated against children and adults with disabilities. Most of you may also be aware that one of OVC's sister organizations within the Office of Justice Programs, the Bureau of Justice Statistics, is currently piloting the inclusion of questions on disability status as well as modifications to the actual sampling frame of the National Crime Victimization Survey in order to capture information on crimes committed against individuals with disabilities. This is important, because as this survey is one of the most comprehensive sources of crime victimization data. It is national in scope. And it relies on self-reports of victims as opposed to reports made to law enforcement.

While we may not have an exact picture of the extent of the violence committed against this population of victims, we do know that stopping the victimization and revictimization of adults and children with disabilities requires the intervention of the criminal justice system, coupled with strong support from victim assistance

providers in partnership, with so many others. This also includes those from the medical, educational, disability service, mental health, and faith communities. But far too often, this never happens, even when a victim with a disability reports the crime to law enforcement.

The barriers that impede effective law enforcement and victim assistance responses are many. Typically, we first think of physical barriers. Those relatively simple but important things such as a lack of ramps or wheelchair access into court buildings and service facilities, or the lack of accessible transportation to and from services. Then there are communication barriers such as the lack of American Sign Language interpreters when law enforcement is called to the scene of a crime and the victim is Deaf. While few in the criminal justice or victim assistance fields would intentionally seek to exclude victims with disabilities, it is attitudes - based on false or shallow stereotypes - that sometimes raise the most daunting barriers. Assumptions are sometimes made that because victims have a disability such as mental retardation or mental illness, they cannot be a credible witness or that their cases are not "winnable."

Attitudes frequently drive many organizational barriers to delivering services. When victim assistance providers attempt to use the resources of the organization in an innovative way to meet the needs of a victim with a disability, they may encounter objections that they are violating policy, or that it is just too expensive to serve these victims. In victim assistance organizations where training has not been provided on disability issues, service providers may mistakenly assume that providing services to these victims is always expensive. They may not understand that there are other resources, especially in the disability community, to assist them with their work. But even when victim assistance agencies work hard to identify and eliminate service barriers, and even when they partner with disability organizations in their community, we know that many crime victims with disabilities never see traditional victim service providers.

In many cases, a clergy member, social worker, doctor, nurse, teacher, or therapist will be the person to whom a victim will tell his or her story. Unfortunately, these professionals do not always receive the education and training they need to understand their role in assessing and screening for victimization, or how to respond when someone discloses, or attempts to disclose, their victimization. At other times, these practitioners may encounter victims who have acquired a disability as a result of their victimization. The practitioner may only focus on the physical and rehabilitative aspects of working with that victim, never acknowledging or understanding that while the person is attempting to adapt to life with a newly acquired disability, he or she is also struggling with the sometimes overwhelming emotional trauma of the victimization. As Director of OVC, I am working to target those practitioners for training and education on victims issues and needs. I also want to ensure cross discipline opportunities that will enrich their professional development and promote the collaboration that is so important in working with victims.

Consequently, it becomes vitally important that those of you who are in daily contact with individuals with disabilities understand the dynamics of abuse and violence - you need to understand that people with severe disabilities may be especially vulnerable to victimization. They may in fact be specifically targeted because of their disability. They may not have the ability to communicate that directly to you, or they may not be able to report the crimes committed against them because of their fear of the perpetrator. They may believe that the only way

to maintain their personal independence is to endure abuse at the hands of care givers. We must also understand that with all victims -child and adult alike- the pain of physical and emotional abuse does not abate when the perpetrator is identified and removed. The trauma of sexual assault does not end with the word "guilty." On the contrary, it has barely begun. Yet all too often, victims with disabilities never receive the services that will help them begin, and continue, their physical and emotional healing.

We are also working to eliminate the added trauma heaped on victims as they work their way through the maze of the criminal justice system. Until very recently, the criminal justice system has not been a hospitable place for any victim. Certainly for victims with severe physical or cognitive disabilities, the challenges and obstacles can be insurmountable without the right support, services and accommodations. We can do better for these victims!

The work that you do during this conference will help us do better. Your findings and recommendations will help map the way for the victims' field, and the many different systems that must join together to stop the violence and ensure that victims have access to justice and needed services. In the meantime, I have a duty to administer the charges of my position, and that includes supporting the thousands of hard-working men and women across the country-men and women like you-who serve crime victims everyday. My vision for OVC encompasses the talent, compassion, ingenuity, and determination of providers like you. I am also taking advantage of the adaptability of victim service practitioners and their allies in many fields. You make whole careers out of borrowing from, building on, and improving approaches implemented elsewhere. I want to use my Office's leverage in expanding those worthy practices.

OVC is about to release two videos on crime victims with disabilities, and I was particularly struck by the comments of a disability advocate in one of the videos. She stated that the disability and victim advocacy communities are very much alike in their struggle for the rights and full inclusion of the people they serve. A victim advocate in these videos talked about the need for these communities to work, not as parallel universes, but as collaborative partners with a wealth of information and resources to share with one another. Both of these advocates are in the audience today, Leigh Ann Davis from The Arc, and Sharon D'Eusanio from The Florida Office of the Attorney General. Sharon and Leigh Ann, I want you to know that we at OVC agree.

At the end of this week, OVC will announce its Fiscal Year 2002 Discretionary Grant Funding Application Kit, which will reflect my goals for the Office. The needs of crime victims with disabilities figure prominently in the kit. Over the course of the next three years, OVC will dedicate over 3 million dollars to a project that will support and unite the efforts of victim assistance, disability advocacy, and other community-based providers to first identify, and then serve, crime victims with disabilities. We are doing this - not because of some legislative mandate - but because it is the right and just thing to do.

I am proud to serve an Administration that recognizes the significance not only of victims' rights, but of victims themselves. But I am also proud to be working by your side and representing your interests. As Attorney General Ashcroft has said, "You have made a difference in the lives of victims and in the strength of your communities and of your nation." And for that, I thank you.

I look forward to working further with each of you in our common goal of stopping the violence and supporting victims. God bless each of you for the wonderful work that you do, and my best wishes for a very successful conference.

VIOLENCE PREVENTION: THE CDC ROLE

John Lutzker, Ph.D. and Joanne Klevens, M.D., Ph.D., M.P.H.

Centers for Disease Control and Prevention

Violence is a leading cause of death, disability, and hospitalization in the United States, and as such, it has been targeted for action in the nation's public health plan (US Department of Health and Human Services, 2000). Suicide is the eighth leading cause of death in the U.S. and the third leading cause among 10-24 year-olds. Homicide is the second leading cause of death among youth ages 15-24 years. A third of all female homicide victims were murdered by an intimate partner. In fact, one of every four women report being assaulted or raped by an intimate partner at some time in their lives. Over 900,000 children experienced maltreatment in the past year and 1200 died because of it. Many of these problems are interrelated.

Because violence as well as unintentional injuries have been recognized as major public health problems, in 1992, the Centers for Disease Control added the National Center for Injury Prevention and Control to its existing centers. The National Center for Injury Prevention and Control has three Divisions: the Division of Violence Prevention, the Division of Unintentional Injury Prevention, and the Division of Injury and Disability

Outcomes and Programs.

The Division of Violence Prevention recently undertook a strategic planning process. We defined our mission as preventing injuries and deaths due to violence through surveillance, research and development, capacity building, communication, partnerships, and leadership. In surveillance, we plan to fully implement a high quality, comprehensive surveillance system, integrated with other CDC surveillance systems for monitoring injuries and deaths due to violence in the United States. In research and development, we hope to ensure that modifiable risk and protective factors for violent deaths and injuries are understood and that the efficacy and effectiveness of promising interventions, programs, and policies have been established. We plan on creating a violence prevention infrastructure across the country to ensure that effective programs are adopted and in place. We would like to facilitate a shift of existing social norms surrounding violence and disseminate information on risk factors and effective programs, creating a consensus about effective approaches to preventing violence. Our goal is to ensure that public health is recognized as a partner in violence prevention efforts.

Numerous federal agencies such as the National Institutes of Health or the Department of Justice conduct research in the area of violence. CDC's National Center for Injury Prevention and Control intends to complement efforts of other agencies by promoting research with direct implications for prevention, and by providing leadership in developing and assessing prevention programs and policies. Currently, these efforts have turned towards primary prevention, that is, preventing violence from occurring in the first place rather than preventing revictimization or dealing with the consequences of violence (National Center for Injury Prevention and Control, 2002).

CDC's efforts to improve public health are based on a systematic approach to collect information and translate that information into action (Mercy, Rosenberg, Powell, Broome, and Roper, 1993). This approach involves four interrelated steps.

First, it defines the problem, which implies clarifying what the problem is and collecting information on its frequency and severity to decide if it is, in fact, a priority for intervention. This also includes ongoing monitoring of such information. The second, step involves establishing factors associated with the problem in order to identify populations at risk and potential causes, especially those that are amenable to intervention. The information generated in step two is used to develop strategies to modify these factors in step three. These interventions are then tested in clinical trials to establish their efficacy and then replicated in different populations and varying contexts to establish their effectiveness. If the intervention is proven to be effective, it is then disseminated for large-scale implementation in step 4.

Applying the public health model to violence among individuals with disabilities

Step 1. Magnitude

Nearly 20 percent of the US population (about 54 million people) currently lives with a disability and this proportion appears to be increasing (National Institute on Disability and Rehabilitation Research, 1998). This makes individuals with disabilities the largest minority in the U.S.. Thus, one of the goals of Healthy People 2010 is to “promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population” (U.S. Department of Health and Human Services, 2000, p. 6-3).

We have already demonstrated that violence is an important public health problem. Thus the question is: are persons with disabilities at greater risk for violence? In a review of 6 studies, Sobsey (1994) found that rates of physical abuse among children with disabilities ranged from 19% to 39%, whereas rates of physical abuse among adults with disabilities range from 33% to 81% (based on 3 studies). Shelley, Ingram, Puett, and Sniezek, (submitted) found lifetime rates of sexual abuse among adults with disabilities ranging from 4% to 79% (8 studies). These rates of violence tend to be higher than those observed in the general population, however, many of these studies are based on clinical and other convenience samples.

There is little information on the rates of violence nationally among individuals with disabilities. The number of states that routinely collect information on disability in child maltreatment cases has declined over the years and only seven states document specific disabilities (Bonner, Crow, Sheila, and Hensley, 1997). Data from the second National Incidence Study (NIS-2), based on a nationally representative sample of 35 Child Protective Services (CPS) agencies in the U.S., suggest that abuse is about 1.7 times higher among children with disabilities compared to children without disabilities (Crosse, Kaye, and Ratnofsky, 1993). Unfortunately, because these data are based on CPS reports, they tend to exclude extrafamilial maltreatment or noncriminalized violence.

Sullivan and Knutson (2000) conducted the only published population-based survey on disability and abuse among children and found that children with disabilities were 3.76 times more likely to be victims of neglect ($p < .001$), 3.79 times more likely to be victims of physical abuse ($P < .001$), 3.14 times more likely to be sexually abused, and 3.88 times more likely to be emotionally abused. However, because the survey was restricted to Omaha, Nebraska, we do not know if the results are generalizable to populations with other characteristics. In fact, a reanalysis of the NIS-2 data suggest that disability is a risk factor for abuse

among white children, but not among African American children (Randall, Sobsey, and Parrila, 2001).

Unfortunately, similar population-based data are lacking for the adult population. Current surveys and surveillance systems in violence have not included disability as a variable in their data collection systems. This points to a significant gap in the information needed for action and that is standardized and systematic collection of violence among individuals with disabilities. Healthy People has called for including a set of standardized questions that identify people with disabilities in all relevant surveillance instruments (USDHHS, 2000, p. 6-9). However, violence was not included in this objective.

Step 2. Circumstances and factors associated

In general, reviews of studies among adults with disabilities show that victims are more likely to be women, whereas perpetrators tend to be men (Shelley et al., submitted; Sobsey, 1994). Perpetrators are often known to the victim and are quite often service providers or family members. Qualitative studies document the complexity of abuse experiences: in addition to emotional, physical, and sexual abuse, individuals with disabilities also experience various forms of disability-specific abuse, for example, damage or removal of assistive devices, theft of valuables or medications, and unwanted sexual touch during assistance with dressing or bathing (Hassouneh-Phillips and Curry, 2002).

Sullivan and Knutson's (2000) population-based survey showed that neglect is the predominant form of child maltreatment, for all children regardless of disability status. However, children with disabilities are more likely to be exposed to multiple forms of maltreatment and multiple episodes of maltreatment. Immediate family members account for the majority of neglect, physical abuse, and emotional abuse among children. Sexual abuse was a bit more likely to be perpetrated by individuals outside the family. Family stress was significantly associated with all types of abuse equally among children with or without disabilities.

Factors associated with an increased risk for violence for all children include: poverty and/or inadequate or lack of access to supportive services, parental substance abuse and history of violence, parents with depression, poor coping skills, low self-esteem, and poor impulse control, lack of knowledge, unrealistic expectations, family stress and lack of social support, disruptions in bonding and attachment, and perceptions that the child is different from others (National Research Council, 1993). Many of these factors are often present in the case of children with disabilities (National Clearinghouse on Child Abuse and Neglect, 2001).

Factors that may contribute to increase risk among the individuals with disabilities include societal and institutional beliefs, practices and policies (such as segregation) that tend to "devalue" individuals with disabilities, consider them fortunate to receive attention, and therefore expect their compliance, or limit their opportunities for education, employment, and mainstream life experiences. (Curry, Hassouneh-Phillips, and Johnson-Silverberg, 2001; Sobsey, 1994). Other beliefs such as believing that individuals with disabilities are insensitive to pain, not vulnerable to abuse or that all caretakers are well meaning and competent may result in lack of awareness and attention to the problem. Many people believe that the people with disabilities are incapable of directing their own lives or making

their own decisions. In addition, there appears to be no comprehensive system to adequately select, train, monitor, or sanction caregivers and agencies providing services to them.

Factors that may contribute to increased risk at the individual level include increased dependence on family and caregivers, low self-esteem, perceived powerlessness and helplessness, and lack of assertiveness skills, restricted social lives and networks, lack of knowledge or access to information and resource, limited cognitive or communication skills, and limited mobility. These factors may explain why individuals with disabilities may have naive beliefs in the good intentions of others, uncertainty about what is acceptable behavior, not know they were victimized or how to report abuse, or believe that mistreatment is part of their plight in life. Although many of these factors seem intuitively logical, most have not been corroborated by empirical research. Thus, such research is necessary to develop programs.

Step 3. Developing and evaluating preventive interventions

Prevention strategies may be aimed at the general public (universal) or target families or settings considered at higher risk (selective) (National Clearinghouse on Child Abuse and Neglect, 2001; Sobsey, 1994).

Raising awareness of the problem might lead to increased funding for filling the research gaps. More appropriate attitudes towards people with disabilities also need to be promoted among the general public by ensuring contact between people with and without disabilities (especially early), educating about people with disabilities, and providing positive models.

Policies might be implemented to promote deinstitutionalization of individuals with disabilities or safer, more pleasant institutional environments (smaller, egalitarian in structure, unregimented, foster interpersonal bonds between caregivers and clients, realistic workload for staff, improve working conditions, set and maintain safety standards, encourage reporting and directly confront abuse). These policies should promote careful screening and training of caregivers, and prevent and treat staff burn out.

Families who have children with disabilities should receive additional support to improve their social network, facilitate attachment and parental relationships, help manage stress, and facilitate access to educational, medical, recreational, and financial programs. Programs focusing on individuals with disabilities should empower potential victims by teaching assertiveness, communications and social skills, and how to recognize and respond to abuse. Whatever the focus of the program, efforts should be made to rigorously evaluate it in order to establish its positive impact and potential adverse effects.

CDC has numerous projects and programs around the U.S. to reduce violence, although none of these target individuals with disabilities specifically. The Division of Violence Prevention has funded various multisite projects to evaluate community coordinated and culturally competent responses to the problem of violence against women as well as more coordinated responses for abused women in which children are involved. It has funded efforts to identify best practices in batterer interventions, develop an evaluation guide for violence against women interventions, and explore social norms about violence against women and children. We also have various multisite projects in schools and families to prevent youth violence as well. We have funded several academic centers of excellence

to promote research, community partnerships, and professional training for reducing youth violence. Projects to prevent child maltreatment include an efficacy trial of a multilevel parenting support intervention, an effectiveness trial of Project Safe Care (Lutzker, Bigelow, Doctor, Gershater, and Greene, 1998), and the systematic identification of promising interventions to prevent or intervene in maltreatment and promote positive parenting. The National Center on Birth Defects and Developmental Disabilities has also funded the evaluation of an intervention to promote better parenting. In addition to these programs, CDC has funded various research projects to enhance our understanding of risk and protective factors for different types of violence and its negative sequelae.

Step 4. Disseminating and implementing interventions

Once effective programs have been identified, guidelines must be developed to insure fidelity in program implementation. Key decision makers and public health opinion leaders must be identified and appropriate methods for communicating the information on effective programs need to be developed. Surveillance systems must be in place to help monitor the impact of intervention.

Summary

In summary, the prevalence of violence against persons with disabilities is higher than among the general population. CDC has put forth a broad agenda, using the public health model, to advance our understanding of violence, to create and evaluate programs to prevent it, and to disseminate effective programs. Though special adaptations may be necessary in applying this model in disabilities, the overarching strategies for that population are consistent with the public health model.

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PREVENTING AND INTERVENING IN VIOLENCE AGAINST CHILDREN AND ADULTS WITH DISABILITIES: THE ROLE OF NIDRR

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Good Morning. I am pleased to be here today to discuss this important topic of violence against individuals with disabilities, and am doubly pleased that NIDRR was able to contribute to the sponsorship of this conference. Along with my colleague, Stephanie Lee, Director of the Office of Special Education Programs, I want to welcome you on behalf of OSERS, our component in the Department of Education. In the spirit of the President's pledge of "No Child Left Behind", we at OSERS are working to see that adults and children with disabilities can achieve their full potential.

The late Barbara Waxman has called violence "disability's dirty little secret". It is more widespread than most people realize, and, for many sometimes understandable reasons, it is often "swept under the rug" by individuals with disabilities as well as others in their environments.

In my talk to you today, I want to discuss four major topics. First is a general brief background on NIDRR, followed by a discussion of the NIDRR research agenda and its relevance to violence prevention, highlights of the research on violence that NIDRR has sponsored, and some reflections on potential next steps.

Basic Facts

First, for some background. NIDRR is located administratively in the Office of Special Education and Rehabilitative Services within the Department of Education.

NIDRR's Mission is to generate, disseminate, and promote the use of knowledge that will:

- Improve the ability of disabled individuals to perform activities in the community, and
- Increase the capacity of society to provide full opportunities and supports for participation.

NIDRR has a wide array of programs and strategies for approaching this very broad mission. To begin, NIDRR develops a research agenda that it is founded on two important guiding documents. One is the New Freedom Initiative announced by President George W. Bush on February 1, 2001. This initiative requires a range of Federal agencies to undertake activities to improve the status of people with disabilities in employment and community living, emphasizing access to assistive technology and environmental accommodations to achieve its goals.

Personal security and freedom from violence are important conditions for realizing the NFI's commitment to full access to community living, and to improving the mental health service system.

NIDRR Research Agenda

The NIDRR Long-Range Plan for 1999-2003 presents a new paradigm for research stating “disability is a product of the interaction of the characteristics of the individual and the characteristics of the natural, built, cultural and social environments.” NIDRR supports research that is holistic and addresses the whole person existing in context of society. NIDRR’s research values are scientific excellence and consumer relevance. And I should emphasize that NIDRR funds applied research, seeking solutions to problems of disabled persons and service providers. NIDRR currently has a major focus on the prevention of secondary complications of disability. What NIDRR does not focus on is primary prevention of disabilities or surveillance.

The Plan provides for research to achieve consumer goals in 5 areas

Employment; Maintenance of health and function; Technology for access and function; Living independently in the community; and Associated areas such as disability statistics and outcomes measurement. The Plan also calls for Knowledge Dissemination and research capacity building.

The Plan encompasses research on violence and abuse under the general headings of independent living, community-based residential services, personal assistance services, community integration and inclusion, and social integration and self-determination.

Congress appropriated \$110 million for NIDRR to carry out its research and related activities under the Rehab Act this year. The funds are distributed among the categories listed on our website (<http://www.ed.gov/offices/OSERS/NIDRR>).

Under its very broad statutory mandate, NIDRR has a number of funding mechanisms for granting this money to public and private organizations, from universities to community groups to businesses. The various funding programs are listed on our website and will give you web addresses to find out more about them. Some of these programs are directed research, in which NIDRR sets the priorities. We have included violence in RRTC and DRRP priorities in the past, but it is not included every year. The Field Initiated program is an investigator-driven program; applicants are free to submit proposals for any area relevant to disability, and some have conducted research on violence under this heading.

NIDRR-Supported Research on Violence

NIDRR research on disability and violence has two tracks: (1) violence as a cause of disability and (2) the vulnerability of disabled persons to violence. NIDRR projects on SCI and TBI address violence as a cause of disability, but I assume that our interest today lies in the second category. About ten years ago, NIDRR held two focus groups - one on independent living and one on women with disabilities - that converged in their conclusion that research on violence and disability should be a priority. NIDRR incorporated research on violence into its priorities at that time.

What research has NIDRR supported on this aspect of disability?

On the one hand I could say it is a limited amount, given the seriousness of the problem. On the other hand, I am proud to say we have supported some of the most important studies and leading researchers in the field. I refer specifically to work by Peg Nosek (1998) and colleagues (Young et al, 1997) at Baylor, Laurie Powers (2002) and her group at Oregon Health Sciences University, Marlene Strong and

Ann Cupolo Freeman (1997) at Berkeley Planning Associates, and Simi Litvak and Karyl Eckels at the World Institute on Disability.

Most of these studies have focused on women with disabilities, and physical disabilities in particular, but I am happy to say that Laurie Powers currently is conducting a study on violence and abuse against disabled men.

What do the studies tell us? It is difficult to reach sweeping conclusions from a few studies, but there is enough evidence to point to problem areas for future study and also to suggest interventions to be tested.

Dr. Nosek's cornerstone study tells us that the incidence of physical and sexual violence against women with physical disabilities is similar to the rate of such violence against women who do not have disabilities. Dr. Powers and her associates have elaborated on a factor that is different — the incidence of violence by caregivers. "Caregivers" includes paid personal assistants, health care providers, and family caregivers.

Abuse and violence by caregivers presents a confounding dilemma for persons with disabilities. Disabled people frequently are dependent on caregivers — whether paid personal assistants, friends and family, and health care providers - for basic necessities of life. It is difficult to recruit and train new personal assistants, not to mention new friends and family! There is no ready backup system for personal assistants and generic community services such as crisis shelters often lack the resources or knowledge to accommodate individuals with disabilities. This leads to the "swept under the rug" phenomenon. The title of one article, "Get Me My Scooter So I Can Leave You" is an ironic and poignant statement of this dilemma.

Individuals with developmental disabilities are at very high risk for abuse from care providers, strangers, and familiars. Unfortunately, the data on violence against people with developmental disabilities, as with other disabilities, is scanty. In a review of available literature from the U.S., Canada, Australia, and Britain (1999), Sobsey (1994) and colleagues (1991) provide a "conservative estimate" that people with developmental disabilities are "four to ten times more likely to be victims of crimes than are people without disabilities." Their study suggests that over 70 percent of women with developmental disabilities are sexually abused during their lifetimes.

A potential source of data in the near future is the National Crime Victimization Survey; the Bureau of Justice Statistics is working to develop measures to identify people with developmental disabilities in that survey, the source of national statistics about crime

What are the suggested remedies to prevent future acts of violence? NIDRR researchers have not conducted large scale tests of interventions, but have observed the need for:

- greater empowerment of disabled persons, especially women, to handle abuse by personal assistants and family members;
- more accessibility and disability awareness in generic programs such as crisis shelters
- backup systems for personal assistants and other support services
- more enforcement, screening, and training for health care providers and staff of mental health institutions

- Training for counselors in the rehabilitation and disability fields, to assist disabled women and men to identify abuse and avoid violence and abuse
- Involvement of peer counselors and centers for independent living

Recommendations for Next Steps

- To begin with, there are not enough data available on nationwide incidence of abuse in various settings. Law enforcement, criminal justice, and health care systems, could be good sources of data about incidence and prevalence and trends. It has been a goal of OSERS that all relevant Federal data collections and surveys should include disability as a category for reporting and analysis. We need to continue and upgrade our surveillance efforts.
- We need to raise the general level of awareness among disabled persons, family members, care providers, and the community at large about the frequency and types of violence against individuals with disabilities. Violence cannot remain “disability’s dirty little secret”.
- We need to test systematically prevention interventions to determine efficacy, and then to provide for implementation of validated interventions. Individuals with disabilities must be involved in the research and in implementing the solutions.
- And, we must develop valid practices to prevent secondary complications and to assist disabled victims of violence to recover physically and psychologically.

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OSEP'S INVOLVEMENT IN ISSUES RELATED TO VIOLENCE AGAINST CHILDREN WITH DISABILITIES

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Background on Disability and Abuse/Neglect:

Child abuse and neglect have some clear relationships to disabilities. While the strength and directions of the relationship merit continuing research, we do know the following:

- * Early child abuse not only results in psychological, emotional and social difficulties, it also has irreversible molecular and neurobiological effects on the developing brain. For example, early maltreatment is associated with a reduction in the size of the adult hippocampus and amygdala, portions of the brain involved with memory and with emotions of depression, irritability and hostility. Other abnormalities of the brain common to children who have suffered abuse are associated with psychiatric disorders including manic-depressive illness, schizophrenia, autism and attention deficit hyperactivity disorder (Teicher, 2002).
- * Preliminary results from the National Survey of Child and Adolescent Well-Being indicate that 84% of children in the long term foster care sample have received supplementary or special education services.
- * Early 1990's data from the National Center on Child Abuse and Neglect found that 14.1% of a nationally representative sample of maltreated children had one or more disabilities. This study also indicated that the incidence of any abuse or neglect for children with disabilities was 35.5 per 1000, while the incidence for all children without disabilities is 21.3 per 1000 (a ratio of 1.67). The ratio of incidence for disabled children to that for nondisabled for physical abuse was 2.09 and for emotional neglect was 2.77 (Westat, 1993).
- * The same study revealed that for 47 percent of the maltreated children with disabilities, child protective services caseworkers reported that disabilities led to or contributed to child maltreatment. In 37% of cases, caseworkers reported that abuse contributed to or resulted in a disability.
- * Several dated smaller scale studies have reported that youth with learning disabilities are more likely to be victims of crime than non disabled peers (Bryan, Pearl and Herzog, 1989) and that students with behavior disorders are more likely to be victims of violent crime than those with LD or MR (Lang & Kahn, 1986).
- * Data from a hospital-based study conducted at the Boys Town National Research Hospital found that among children identified as maltreated, 64% were found to have some disability, compared to 32% of the nonabused control group (Sullivan & Knutson, 1998). Another study using school-based data found that among public schools, 22% of maltreated children had an identified disability, compared to 9% of nondisabled who were maltreated. The authors concluded that the relative risk for maltreatment among children with disabilities is 3.44 times that of non disabled children (Sullivan & Knutson, 2000). Children with emotional disturbance and mental retardation were significantly more likely to be neglected than children with other disabilities.

OSEP's Involvement

The Office of Special Education Programs (OSEP) has four major activities or focus areas related to the prevention of child abuse and neglect of persons with disabilities. These four areas are (1) Strong proactive prevention activities and investments, (2) Direct support of research on child neglect and children with disabilities through National Institutes of Health, (3) Participation in interagency activities about child abuse and neglect, and (4) Strong self-determination and self-advocacy investments.

(1) Proactive prevention activities and investments

OSEP has long supported research on the use of positive behavioral interventions and supports as a system for preventing and intervening with challenging behaviors of children and youth with disabilities. Our recent investments in the OSEP Technical Assistance Center on Positive Behavioral Interventions and Supports and the National Center on Education, Disability and Juvenile Justice (EDJJ) result in research and dissemination of the best practices on the use of proactive prevention strategies. They also examine and provide technical assistance for creating and maintaining effective environments that link research-validated practices and the environments in which teaching and learning occur. Lessons from these investments that apply to efforts to prevent abuse and neglect of children with disabilities include:

- * Risk factors such as cognitive deficits, hyperactivity, risk-taking, and early involvement in antisocial behavior are associated with violent behaviors in youth.
- * Early exposure to patterns of antisocial behavior places a child at increased risk for later violent behavior.
- * External risk factors that predict early onset and chronic patterns of antisocial behavior include parental criminality, harsh and ineffective discipline, family conflict and child abuse and neglect.
- * School related risk factors are also associated with youth antisocial and violent behavior. These include a lack of involvement in school activities by students, absence of clear rules and school policies governing behavior and few allowances for individual differences in the school.
- * Because schools can serve a protective role in the provision of safe and effective learning environments for children at risk for antisocial behavior due to external factors such as abuse and neglect, we must provide schools with the capacity to establish and sustain positive and effective school climates for all students.
- * Through its investments, OSEP supports the adoption of a sustained, positive, preventive and instructional approach to school-wide discipline and behavior management. This approach of school-wide positive behavioral support (PBS) relies on early prevention, and provision of a continuum of programs and systems to support those children with the most intensive needs. PBS utilizes science-based practices based on scientific evidence.

Given the crucial involvement of the child welfare system in the protection of children with disabilities, OSEP has funded an inservice training program at Georgetown University to teach child welfare professionals about timely referral of children for evaluation, and to effectively work with agencies serving young children with disabilities. Georgetown's program also describes the impact of

disabilities on families and provides strategies for improving the family's ability to respond to a child's special needs. The major target audiences for the curriculum are child welfare intake specialists who respond to the initial and ongoing reports of child abuse and neglect, family preservation workers who work intensively with families, and foster care and adoption workers who provide support to families responsible for the care of children within the child welfare system. The importance of these individuals in creating positive experiences in the lives of children with disabilities cannot be underestimated.

(2) Direct support of research on child neglect and children with disabilities through NIH

OSEP participates as an active member of the National Institutes of Health Child Abuse and Neglect Working Group, and the related Federal Child Neglect Research Consortium, led by the National Institutes of Mental Health and the National Institute of Child Health and Human Development. Through this activity we contribute support to three interdisciplinary research studies that examine the prevalence and impact of abuse and neglect on children and youth with disabilities, as well as the efficacy of services for this special needs population.

The three studies which we directly support include:

Child Neglect: Cross Sector Service Paths and Outcomes, Melissa Jonson-Reid, Washington University, St. Louis, MO

Processes Linking Child Neglect and Adaptation to School, Michael Lynch, Hope Family Center, Rochester, NY

Predicting and Preventing Neglect in Teen Mothers, John Borkowski, University of Notre Dame

(Abstracts of each of these projects are listed in the Appendix.)

(3) Participation in interagency activities around child abuse and neglect

In 1994 OSERS initiated around national dialogue on issues of child abuse and neglect of persons with disabilities by sponsoring a National Symposium on Abuse and Neglect of Children with Disabilities. Since that time, we have continued to take advantage of collaborative relationships with other agencies responsible for investments in research on abuse and neglect.

For example, OSEP has been involved in the design and now the review of findings from the on-going National Survey on Child and Adolescent Well-Being (NSCAW) by the Administration on Children, Youth, and Families. NSCAW is the first survey to collect detailed information on a national probability sample of children and families in contact with the child welfare system.

Our involvement in this conference is another example of our dedication to improving research on and services to children with disabilities who are abused and neglected.

Background on NSCAW:

In 1996, Congress directed the Secretary of the Department of Health and Human Services to conduct a national study of children who are at risk of abuse or neglect or are in the child welfare system. Congress directed that the study include a longitudinal component that follows cases for a period of several years; collect data on the types of abuse or neglect involved, agency contacts and services, and out-of-home placements; and yield reliable state-level data for as many states as feasible. In response, the Administration on Children, Youth, and Families and the

Office of the Assistant Secretary for Planning and Evaluation have undertaken the National Survey of Child and Adolescent Well-Being.

The NSCAW will make available for the first time nationally representative longitudinal data drawn from first-hand reports from children and families or other caregivers as well as from service providers. Moreover, this is the first national study that examines child and family well-being outcomes in detail and seeks to relate those outcomes to their experience with the child welfare system.

Overall, the study will address crucial program, practice, and policy issues in two broad areas:

Dynamics of the child welfare system: What are children's paths into and through the child welfare system? What individual, family, system, and other factors affect investigation, services, placements, and the length of involvement?

Outcomes: What are the long-term and short-term outcomes for children and families who enter the child welfare system in terms of safety, well-being, and permanence?

In the short-term, the study will provide information on the former, including (1) the characteristics of children and families most likely to come into and stay in the child welfare system; (2) the characteristics associated with those who enter the system and those who do not; (3) the service needs of children and families; and (4) the kinds of services actually provided. In the long-term, the study is designed to examine the relationship between services provided and outcomes achieved for various types of children and families over time.

Recent preliminary data regarding the receipt of special education and supplementary services by children who have been in out-of-home foster care for at least one year. Twenty-three percent (23%) of all children in this sample receive special education services. Severity of maltreatment appears to influence the need for special education: 56% of children whose most serious abuse type was physical abuse have received special education, compared to 27% of children with a most serious abuse type, which is failure to provide for basic needs.

(4) Our strong self-determination and self-advocacy investments

OSEP has a long commitment to supporting research on the use of strategies to enhance the self-determination of persons with disabilities. Self-determination is defined as the combination of skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior (Algozzine et al., 2001). Common features of self-determination interventions include teaching choice-making to individuals with moderate and severe mental retardation and teaching self-advocacy to individuals with learning disabilities or mild mental retardation. Components typically include choice-making, decisionmaking, problem solving, goal setting and attainment, self-advocacy, self-efficacy, self-awareness and understanding, and self-observation, evaluation, and reinforcement. Self-determination skills and outcomes may be of particular importance with respect to preventing abuse and neglect of children and youth with disabilities.

* Children and youth with disabilities, particularly those with cognitive disabilities, are often taught to be compliant in social, educational, and vocational settings.

- * This compliance, while conducive to maintenance of certain learning environments, may have negative implications for youth who are at risk of abuse and neglect by their caregivers or other authority figures.
- * Mastery of self-advocacy skills may be an important “inoculation” against neglect and abuse, both sexual and physical, of young persons with disabilities.

Appendix:

Projects supported by OSEP through the Federal Child Neglect Research Consortium:

“Child Neglect: Cross-Sector Service Paths and Outcomes.” Melissa Jonson-Reid, P.I., Washington University, St. Louis, Missouri.

This study will conduct a large-scale longitudinal analysis of cross-sector service utilization by neglected children and their families (subdivided by types of neglect) which is linked to outcomes at the family (e.g., reunification, etc.) and child (e.g., death, incarceration) levels. Using administrative data drawn from education, health, juvenile justice and social service agencies, this accelerated panel study compares the cross-sector service paths and outcomes of children receiving AFDC and reported to child welfare agencies for neglect; physical abuse; sexual abuse; and more than one type of maltreatment compared to a matched group of children in families receiving AFDC, but not reported to child welfare agencies. Analyses will be conducted within an eco-developmental framework, examining the influence of neglect while controlling for child, family, service sector use and community level factors.

“Processes Linking Child Neglect and Adaptation to School.” Michael Lynch, P.I., Hope Family Center, Rochester, New York.

This grant proposes a longitudinal investigation of the impact of parental neglect on school adjustment and academic performance in children ages 4 to 6 years old. The study aims to confirm previous links between child neglect and poor school performance and examine possible mediators and moderators of the links between neglect and poor adaptation to school, including attachment security, self-esteem, verbal and cognitive abilities and readiness to learn, maternal mental health, poverty, and domestic and community violence. Three cohorts of children will be recruited at age 4 and followed to the end of the first grade in order to test an ecological-transitional model of the impact of child neglect.

“Predicting and Preventing Neglect in Teen Mothers.” John Borkowski, P.I., University of Notre Dame.

This grant supports a program of research across four sites to clarify the meaning and measurement of neglect in adolescent families, develop and test the accuracy of a screening tool to predict neglect, assess the impact of varying degrees and types of neglect on children’s development, test and refine the Notre Dame Adolescent Parenting Conceptual Model, and investigate the relationship between child neglect and child development. Based on the results of these research activities, the investigators will design and implement a series of studies to test, through randomized, controlled trials, the effectiveness of highly promising interventions to prevent neglect and improve the caregiving environment for infants of adolescent mothers.

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VIOLENCE AGAINST PERSONS WITH DISABILITIES: WHO ARE THE MOST VULNERABLE?

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Introduction

Violence in American society is an issue of great concern. There are all kinds of violence. There is physical violence, as well as psychological violence. The Centers for Disease Control (as cited in Rhode Island Department of Health, 2002) defines violence as “the threatened, or actual use of physical force or power against another person, against oneself, or against a group or community which results in or has a high likelihood of resulting in injury, death, or deprivation.” The whole continuum of threat against persons with disabilities, and others, must be addressed. Violence is related to the issue of power; those who have power use violence against those who lack power.

National trends show that there has been a decrease in overall violence over the last twenty years in the United States; this refers to reported crime. According to the Bureau of Justice Statistics (2001), violent crime rates have declined since 1973, reaching the lowest level ever recorded in 2000 (45% versus 25%). The incidence rate of reported crime for both men and women declined during the same period. The comparison for males is 70% (1973) versus 30% (2000) and for females is 30% (1973) versus 24% (2000). The figures cited are for reported crime. We are not certain what the trends are with regard to the incidence of violent crimes against persons with disabilities since the vast majority of these crimes are unreported.

Individuals with Disabilities face numerous challenges relative to violence and interactions with their environment. The U.S. Equal Employment Opportunity Commission (as cited in Marge, 2002) defines disability as “a physical or mental impairment that substantially limits one or more of the major life activities of an individual.” Persons with disabilities who may have limitations in mental or physical functioning, such as vision, hearing, talking, walking, may be at greater risk for serious harm than persons without disabilities (Marge, 2002).

The exact prevalence of violence against individuals with disabilities is unknown. Information is available relative to specific types of abuse. Sexual violence has been investigated more widely among people with cognitive impairments than among people with other types of disabilities. For adults with cognitive impairments, reported rates for lifetime experience of sexual violence range from 25% to 67% (National Center for Injury Prevention and Control, 1998).

Reynolds (1997) identifies three reasons for the vulnerability of persons with mental retardation and other cognitive disabilities to sexual violence: 1) social powerlessness; 2) communication skill deficits; and 3) diminished ability to protect oneself due to lack of instruction and/or resources and impaired judgement. Systematic factors that increase the risk of being abused include family isolation and stress, separation from the home and a system that has strong roots in a

tradition of rewarding compliant attitudes among people with developmental disabilities (Valentini-Hein & Schwartz, 1995 as cited in Reynolds, 1997).

According to research, most individuals with disabilities will experience some form of sexual assault or abuse. The rate of sexual victimization in the general population is alarming, yet largely goes unnoticed. At least 20 percent of females and 5 to 10 percent of males are sexually abused every year in the United States. Although these figures are disturbingly high, people with mental retardation and other developmental disabilities are at an even greater risk of sexual victimization (Reynolds, 1997). Comparing the percentages of sexual violence victims who have disabilities with the percentages of sexual violence victims who do not have disabilities is difficult because of the differences in the terminology and methods used to determine these rates. However, persons with disabilities are at a higher risk for sexual violence than are persons without disabilities (National Center for Injury Prevention, 1998).

Perpetrators of Violence

Persons with disabilities are abused primarily by caregivers, whether they are family members or disability service providers. According to Wolbring (1994), perpetrators of sexual abuse in the case of individuals with disabilities are natural family members (15-25%), acquaintances and neighbors (15%), disability service providers (30%), and strangers (5%). Most perpetrators are male (88%-98%) and are known to the victim (National Center for Injury Prevention and Control, 1998). These perpetrators of violence and the intimate physical and emotional contact involved in the care they provide greatly increases the risk of abuse to persons with disabilities (National Clearinghouse on Family Violence, 1992).

The settings for abuse are the same for those without disabilities. The living arrangements of individuals with mental retardation, for example, can also place them in a highly vulnerable situation (Reynolds, 1997). Residences, particularly the victim's home, are the most common place for episodes of sexual violence. Other venues include vehicles, places of employment, public areas, schools, and day or leisure facilities (National Center for Injury Prevention and Control, 1998).

Residence in an institution also places persons with disabilities at risk for violent crime. Research has found that the risk of sexual abuse in an institutional setting, such as residential and group homes, is two to four times as high as the risk when the individual is in the community (Sobsey & Mansell, 1990). Institutionalization is a dynamic of living in a large facility and involves an approach whereby one group of people makes decisions for another. Decisions may include when and where a person goes; what is worn; who is visited; what is eaten; and when, how, and by whom health care is received. Parents, teachers, staff, and health care providers hold powerful decision-making responsibilities for the lives of the individuals they serve, deciding when people receive assessment, intervention and treatment and when they do not. It is the "not" that may contribute to abuse (Focht-New, 1996).

Domestic Violence

A recent national study by the Center for Research on Women with Disabilities shows that women with physical disabilities experience about the same rate of emotional, physical, and sexual abuse as women without disabilities. Nearly 55% of each group experienced physical or sexual abuse. The women with disabilities,

however, were more likely to experience the abuse over longer periods of time (Nosek, Howland, Rintala, Young, & Chanpong, 1997).

Women with disabilities are at increased risk for emotional, physical, and sexual abuse. Personal abuse is a significant health risk for women with disabilities, who are at greater risk for abuse than non-disabled women. They experience the same types of abuse from intimate partners, as do women without disabilities. However, their disabilities may place them at additional risk, and the barriers to ending the abuse can be much greater than for women without disabilities (Curry, 2001).

The single largest factor affecting the incidence of family violence against women with disabilities is the extent of these women's "families." Family violence, in this context, refers to physical, psychological or sexual maltreatment, abuse or neglect of a woman with disabilities by a relative or caregiver. Women with disabilities must often depend on a variety of people to provide them with assistance in carrying out their everyday lives. For this reason, their "family is understood to include not only parents, husbands, boyfriends and other relatives, but also friends, neighbors and caregivers (National Clearinghouse on Family Violence, 1992).

Addressing the specific needs of women with disabilities is a challenge. Women with disabilities are a vulnerable group of women whose specific needs with regard to the problem of abuse are just beginning to be understood. In addition to the devastating effects of emotional, physical, and sexual abuse experienced by women in general, women with disabilities may also suffer from other forms of abuse that are specifically related to their disability (Curry, 2001). The National Clearinghouse on Family Violence (1992) lists several examples of violence against women with disabilities:

- neglect: denial of food, lack of or inappropriate personal or medical care;
- physical abuse: assault, or rough or inappropriate handling, inappropriate personal or medical care, over-use of restraint, inappropriate behavior modification, overmedication, confinement;
- psychological abuse: verbal abuse, intimidation, social isolation, emotional deprivation, denial of the right to make personal decisions, threat of having her children taken away;
- sexual abuse: denial of a woman's sexuality, denial of sexual information/education, verbal harassment, unwanted sexual touching, assault, forced abortion or sterilization; and
- financial exploitation: denial of access to and control over her own funds, misuse of financial resources.

In addition to these specific types of abuse experienced by all women, women with disabilities are often abused by the withholding of needed orthotic equipment, medications, transportation, or essential assistance with personal tasks, such as dressing or getting out of bed (Nosek, Howland, Rintala, Young, and Chanpong, 1997).

Leaving abusive relationships is difficult for women with and without disabilities. For many women, leaving an abusive relationship means a move toward greater independence. For women with disabilities, leaving may mean losing their independence and the risk of institutional care (Curry, 2001). Battering

undermines self-esteem and can make a woman feel she is somehow responsible for her own abuse. This situation is even more difficult for a woman with a disability. She may be dependent on her abuser for affection, communication and financial, physical, and medical support (National Clearinghouse on Family Violence, 1992).

Isolation and intimidation are tools used by perpetrators to keep abused women with disabilities from disclosing their abuse and seeking the support necessary for leaving the relationship. Many women with disabilities may not be able to independently make a telephone call or physically leave. Even if women are able to seek help, they may not have access to information about existing services for victims of violence, they may not be able to contact these services if they do not have communication devices such as Telecommunication Devices for the Deaf (TDDs), and they may be afraid of being misunderstood or not believed (Carlson, 1997; Crossmaker, 1991; Furey, 1994; Womendez & Schneiderman, 1991 as cited in Curry, 2001). The reality and or perception of a lack of options may leave women with disabilities feeling powerless and isolated (National Clearinghouse on Family Violence, 1992).

Effects of Violence on Self-Worth

Violence and abuse effect the self-worth and continuing development of people with and without disabilities. The exposure to violence places individuals at risk for the development of emotional disorders. Some of the emotional disorders accounted for are: aggressive behavior, inappropriate anger, poor sense of personal safety, nightmares, emotional detachment, dissociative episodes, inappropriate touching, inappropriate sexual comments, regression, few friends, and self-abuse (Wolbring, 1994).

Sexual abuse, in particular, causes harmful psychological, physical and behavioral effects. Tower (as cited in Reynolds, 1997) states that individuals who experience chronic abuse by a known, trusted adult at an early age suffer more severe damage compared to those whose abuse is perpetrated by someone not well known to the victim, begins later in life, and is less frequent and non-violent.

Recommendations

Perpetrators of sexual crimes often purposefully select people whom they perceive as powerless, vulnerable and/or unable to accuse them (Furrey, 1994 as cited in Pillay & Sargent, 2000). Empowerment practices are paramount to intervening and offsetting the incidence of violent acts committed against persons with disabilities. Empowerment refers to having a sense of controlling one's destiny to a certain extent. The perception of oneself as having power over the forces that control one's life is essential to one's mental health and successful development. Power or lack of power then becomes a critical issue in people's lives (Pinderhughes, 1983). Advocates, family members, service providers, and research and policy professionals have a role to play in the empowerment of persons with disabilities.

There are many individuals with disabilities that can make tremendous contributions to this society. However, these individuals must be empowered to control their environment. Since most violence occurs in isolation, it is imperative that individuals who experience violence are empowered to alert authorities that they are being abused. On a practical level, one treatment goal related to the victimization is acquisition of an understanding of the importance of self-protection and related skills. Sobsey (as cited in Carlson, 1997) states that personal

safety skills are patterns of behavior that are intended to reduce an individual's risk for abuse, exploitation, and violence. This could include training in self assertion and how to call for assistance from the police or others. It is recommended that formal training modules be developed to provide technical assistance that will enable persons with disabilities to set the agenda for what happens to them.

The major outcome of the self-protection goal should be the development of a concrete, personal safety plan that minimally has two components: a safe place to stay and the means of getting there. The safe place can be the home of a supportive family member, friend, or neighbor; a motel; or domestic violence family shelter (Carlson, 1997). Services such as shelters and temporary housing for persons experience domestic violence need to have staff that are knowledgeable about disability issues and facilities that are accessible.

Women with physical disabilities may have more difficulty obtaining help to deal with abuse. They may lack information on domestic abuse services or existing services may be physically inaccessible (Swedlund & Nosek, 2000). In addition to being physically accessible, shelters must be programmatically accessible. This includes the presence of interpreters or assistive technology, understanding of the multi-faceted nature of disability, and needs that are person specific.

Violence escalates from small incidents to larger, more forceful and harmful occurrences. Violence is often initiated by verbal abuse and progresses to pushing and shoving. As it continues, violence escalates into physical abuse. It is essential that individuals with disabilities be empowered to control their own environment and destiny.

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