



Committee on
Law and Justice

Crime Victims with Developmental Disabilities

REPORT OF A
WORKSHOP

NATIONAL RESEARCH COUNCIL

Crime Victims with Developmental Disabilities

Report of a Workshop

Committee on Law and Justice

Joan Petersilia, Joseph Foote, and Nancy A. Crowell, *Editors*

Commission on Behavioral and Social Sciences and Education

National Research Council

NATIONAL ACADEMY PRESS
Washington, DC

NATIONAL ACADEMY PRESS • 2101 Constitution Avenue, N.W. • Washington, D.C. 20418

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

The study was supported by Contract/Grant No. 1999-IJ-CX-0031 between the National Academy of Sciences and the National Institute of Justice. Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the view of the organizations or agencies that provided support for this project.

Suggested citation: National Research Council (2001), *Crime Victims with Developmental Disabilities: Report of a Workshop*. Committee on Law and Justice. Joan Petersilia, Joseph Foote, and Nancy A. Crowell, editors. Commission on Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

International Standard Book Number 0-309-07318-9

Additional copies of this report are available from National Academy Press, 2101 Constitution Avenue, N.W., Washington, D.C. 20418

Call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area)

This report is also available online at <http://www.nap.edu>

Printed in the United States of America

Copyright 2001 by the National Academy of Sciences. All rights reserved.

THE NATIONAL ACADEMIES

National Academy of Sciences
National Academy of Engineering
Institute of Medicine
National Research Council

The **National Academy of Sciences** is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Bruce M. Alberts is president of the National Academy of Sciences.

The **National Academy of Engineering** was established in 1964, under the charter of the National Academy of Sciences, as a parallel organization of outstanding engineers. It is autonomous in its administration and in the selection of its members, sharing with the National Academy of Sciences the responsibility for advising the federal government. The National Academy of Engineering also sponsors engineering programs aimed at meeting national needs, encourages education and research, and recognizes the superior achievements of engineers. Dr. William A. Wulf is president of the National Academy of Engineering.

The **Institute of Medicine** was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility given to the National Academy of Sciences by its congressional charter to be an adviser to the federal government and, upon its own initiative, to identify issues of medical care, research, and education. Dr. Kenneth I. Shine is president of the Institute of Medicine.

The **National Research Council** was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. Functioning in accordance with general policies determined by the Academy, the Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine. Dr. Bruce M. Alberts and Dr. William A. Wulf are chairman and vice chairman, respectively, of the National Research Council.

COMMITTEE ON LAW AND JUSTICE

- Charles F. Wellford (*Chair*), Center for Applied Policy Studies and
Department of Criminology and Criminal Justice, University of
Maryland
- Alfred Blumstein, H. John Heinz III School of Public Policy and
Management, Carnegie Mellon University
- Ruth Davis, The Pymatuning Group, Inc., Alexandria, Virginia
- Jeffrey Fagan, School of Law, Columbia University Law School
- Darnell Hawkins, Department of African American Studies, University of
Illinois at Chicago
- Philip Heymann, Center for Criminal Justice, Harvard Law School
- Candace Kruttschnitt, Department of Sociology, University of Minnesota
- Mark Lipsey, Department of Psychology and Human Development,
Vanderbilt University
- Colin Loftin, School of Criminal Justice, State University of New York at
Albany
- John Monahan, School of Law, University of Virginia
- Daniel Nagin, H. John Heinz III School of Public Policy and Management,
Carnegie Mellon University
- Joan Petersilia, School of Social Ecology, University of California, Irvine
- Peter Reuter, School of Public Affairs, University of Maryland
- Wesley Skogan, Center for Urban Affairs, Northwestern University
- Cathy Spatz Widom, Departments of Criminal Justice and Psychology,
State University of New York at Albany
- Kate Stith, School of Law, Yale University
- Michael Tonry, School of Law, University of Minnesota
- Nancy Crowell, *Study Director*
- Karen Autrey, *Senior Project Assistant*

Preface

The Committee on Law and Justice (and its predecessor, the Committee on Research on Law Enforcement and Criminal Justice) has conducted work on criminal justice and related issues since 1975, when it was formed at the request of the administrator of the Law Enforcement Assistance Administration. The committee applies the knowledge and tools of the social and behavioral sciences to the development of improved policy, research, and evaluation related to criminal and civil laws and the operations of the justice system. It does so primarily by synthesizing, analyzing, and evaluating relevant scientific research related to critical issues in crime and justice at the federal, state, and local levels.

For fiscal year 1999, the committee was asked to conduct activities related to the criminal victimization of people with developmental disabilities. This activity arose under provisions of the Crime Victims with Disabilities Awareness Act (Public Law 105-301), which directed the attorney general of the United States to conduct “a study to increase knowledge and information about crimes against individuals with developmental disabilities that will be useful in developing new strategies to reduce the incidence of crimes against those individuals” (Section 4(a)). The statute authorized the attorney general to contract with the National Academy of Sciences to undertake this study.

The National Research Council (NRC) of the National Academies, in consultation with the National Institute of Justice, U.S. Department of Justice, determined that insufficient research on criminal victimization of

people with disabilities existed to warrant a consensus panel study by the NRC. Instead, a workshop to discuss the state of the research and highlight gaps in knowledge was deemed the appropriate mechanism. The Committee on Law and Justice convened the Workshop on Crime Victims with Developmental Disabilities on October 28-29, 1999, in Irvine, California, at which authors of several commissioned papers delivered the results of their research. The workshop brought together policy officials from the Department of Justice, the Department of Health and Human Services, the Department of Education, the California Department of Developmental Services, and representatives from academia and the public sector. The latter included primarily criminologists, economists, law enforcement officials, policy analysts, psychologists, sociologists, members of the legal profession, and statisticians who have studied victimization of vulnerable populations, generally, and that of people with developmental disabilities, specifically.

Presentations and discussions focused on conceptual issues, including:

- Definitions and measurements;
- The ways in which theory on crime victimization can be applied to vulnerable victim populations;
 - The existence of common themes or elements with regard to victimization experiences of vulnerable groups that would permit better measurement of rare or stigmatizing events that people are reluctant to report;
 - The nature and adequacy of criminal justice and social service systems' response to vulnerable victims, especially those with developmental disabilities; and
 - Whether research information from different sources within criminal justice system reports, surveys, and research studies on victims with disabilities and other vulnerable victim groups can be combined in ways better to inform the design of a new generation of studies on vulnerable victims.

In developing the workshop, the committee drew on information and expertise from other National Research Council work related to this topic, other research, and international, national, state, and local databases and reports.

The chapters in this report draw on the eight papers presented at the workshop. The report also draws on the oral presentations of paper authors

and on comments made by a panel of distinguished commentators at the workshop. A list of the papers and authors appears in the Appendix.

The report draws attention to gaps in knowledge about the criminal victimization of people with disabilities. It is my hope that this report will stimulate research to begin to fill those gaps.

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Research Council (NRC). The purpose of this independent review is to provide candid and critical comments that will assist the institution in making the published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process.

We thank the following individuals for their participation in the review of this report: Linda Cottler, Department of Psychiatry, Washington University School of Medicine; William F. Eddy, Department of Statistics, Carnegie Mellon University; Susan Herman, National Center for Victims of Crime, Arlington, Virginia; Robert Scott, Center for Advanced Study in the Behavioral Sciences, Stanford, California; and James Short, Department of Criminology, Washington State University.

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the report nor did they see the final draft of the report before its release. The review of this report was overseen by Charles Wellford, Center for Applied Policy Studies, University of Maryland. Appointed by the Commission on Behavioral and Social Sciences and Education, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Joan Petersilia
Workshop Chair

Contents

1	Introduction	1
2	Nature and Extent	5
3	Risk Factors for People with Disabilities	22
4	Measurement Issues	32
5	Criminal Justice System Responses	41
6	Treatment Issues	57
7	Research Needs: Statement by the Workshop Chair	63
	References	68
	Appendix: Workshop Materials	81

Introduction

Although violent crime in the United States has declined over the past five years, certain groups appear to remain at disproportionately high risk for violent victimization. In the United States, people with developmental disabilities—such as mental retardation, autism, cerebral palsy, epilepsy, and severe learning disabilities may be included in this group. While the scientific evidence is scanty, a handful of studies from the United States, Canada, Australia, and Great Britain consistently find high rates of violence and abuse affecting people with these kinds of disabilities.

A number of social and demographic trends are converging that may worsen the situation considerably over the next several years. The prevalence of developmental disabilities has increased in low-income populations, due to a number of factors, such as poor prenatal nutrition, lack of access to health care or better perinatal care for some fragile babies, and increases in child abuse and substance abuse during pregnancy. For example, a recent report of the California State Council on Developmental Disabilities found that during the past decade, while the state population increased by 20 percent, the number of persons with developmental disabilities in California increased by 52 percent and the population segment with mild mental retardation doubled (Frankland, 1996).

In addition, because of deinstitutionalization and new legislation, particularly the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, many people with developmental disabilities now live in un-

safe community settings where they get little health care, have access to few social services, and are easy targets for criminal predators. Fully a third (34 percent) of adults with disabilities live in households with a total income of \$15,000 or less, compared with only 12 percent of those without disabilities (Harris, 1998).

WORKSHOP IMPETUS

Because of a growing concern among parents and advocates regarding possible high rates of crime victimization among persons with developmental disabilities, Congress, through the Crime Victims with Disabilities Awareness Act of 1998, requested that the National Research Council of the National Academy of Sciences:

conduct a study to increase knowledge and information about crimes against individuals with developmental disabilities that will be useful in developing new strategies to reduce the incidence of crimes against those individuals. The study . . . shall address such issues as: (1) the nature and extent of crimes against individuals with developmental disabilities; (2) the risk factors associated with victimization of individuals with developmental disabilities; (3) the manner in which the justice system responds to crimes against individuals with disabilities; and (4) the means by which states may establish and maintain a centralized computer database on the incidence of crimes against individuals with disabilities within a state.

Because of the scarcity of empirical research on these issues, the National Research Council and the U.S. Department of Justice agreed that the best way to fulfill this mandate was to convene a workshop, rather than a full-scale study, to bring together researchers, practitioners, legal scholars, and advocates to discuss the state of knowledge in this area and highlight gaps in the research. This report provides details of important issues that were discussed at the workshop but, under National Research Council rules for workshop reports, does not draw definitive conclusions nor make recommendations.

For the purposes of this request, the legislation further defined developmental disabilities, in accordance with P.L. 42 § 6001(8), as follows:

The term developmental disability means a severe, chronic disability of an individual 5 years of age or older that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity—self-care; receptive and expressive language; learn-

ing; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

As we discuss in this report, there are many different definitions of disability that have been used in research and data collection. However, these definitions do not necessarily coincide with the legal definition cited above.

A number of factors have impeded data collection and research efforts on the victimization experiences of vulnerable populations, including those with developmental disabilities. One involves reporting problems associated with vulnerable victims and stigmatizing events—for example, the reporting of sexual abuse of young children, elderly people, or people with disabilities who are dependent on caregivers. A second factor involves the problem of how to identify individuals with developmental disabilities and the behaviors against them that constitute crimes. A third is the apparent weakness of criminal justice system responses when cases that involve vulnerable victims are reported to the authorities. In general, there is a paucity of information about the characteristics of victims and offenders, as well as the interpersonal dynamics and contextual factors that may lead to abuse, neglect, and exploitation.

SCOPE OF THE REPORT

This report draws primarily on the papers and other presentations that were made at the October 1999 workshop. It addresses the following broad questions listed in the National Research Council's proposal:

- What is known about the nature and extent of crimes against vulnerable victims, including persons with developmental disabilities, and the risk factors associated with victimization, and what more do we need to know in order to reduce these crimes?
- What are the personal and social consequences of victimization of the disabled and how can these be ameliorated?

- What is the importance of place and context in understanding crimes against the developmentally disabled, as well as other vulnerable groups, and how can we better understand the dynamics and interaction of caregiver, victim, and context in order to provide improved public safety for this population?
 - How can statistics on the victimization of vulnerable populations, including the developmentally disabled, be developed or improved?
 - How do the justice and social service systems currently respond to crimes against the developmentally disabled, and how can that response be improved?

Because of the lack of research in this area, the studies of victimization cited by workshop paper authors in this report are few, and most have major methodological flaws. They frequently lack well-designed sampling frames, validated interview methods and protocols, and control groups. For these reasons, no firm conclusions about the major questions contained in the legislation cited above can be drawn from them.

Still, these studies do document a serious victimization problem among people with developmental disabilities. While we cannot draw valid comparisons with victimization rates for other groups, both the nature of the crimes directed against the population with disabilities and the level of harm these crimes inflict suggest to the paper authors and the editors of this report that better research is necessary if society is to protect these most vulnerable citizens. It is in this context that the results of extant research on the victimization of people with disabilities are discussed.

Nature and Extent

Although individuals with disabilities have been victimized throughout history, today society is gaining new respect and concern for the civil rights of these vulnerable people. Still, as this process occurs, there are more questions than answers about the nature and extent of criminal victimization of men, women, and children with disabilities. This chapter draws primarily on the workshop papers by Ruth Luckasson, Patricia Sullivan, and Richard McCleary and Douglas Wiebe, as well as the workshop presentation by Mary Ann Curry and Laurie Powers. Brief biographies of the authors of papers summarized in this report can be found in the Appendix.

DEFINITIONS

What Constitutes a Disability?

Disabilities come in many forms, and definitions of disability relate to physical, cognitive, or behavioral characteristics, as well as to an individual's ability to perform specific functions. For example, the ability to see, hear, talk, walk, climb stairs, lift, and carry are considered in some definitions, and the ability to perform the tasks involved in independent living, such as housework, or to participate normally in schooling or other social contexts are considered in others. A person with a severe disability is unable to

perform one or more essential activities, requires some kind of assistive device, or needs assistance from another person to perform basic tasks.

Census data from 1994-1995 indicate that about 21 percent of the U.S. population has some form of disability, and that among the 84 million infants, children, and youth ages 0 to 21, 10 percent (8.4 million)—mostly those ages 6 to 14—have a disability. Census data also indicate that among children ages 0 to 14, 1 percent have a severe disability.

Children and youth with emotional and behavioral problems that require residential treatment are a burgeoning population in the United States. Current estimates from the U.S. Department of Health and Human Services (1999) indicate that some 77,200 children and youth reside in psychiatric settings and group homes in this country and that an additional 70 million children and youth are in out-of-home care, including foster care and kinship care. Medical conditions requiring health care have been identified in 60 percent of children placed in foster care; children placed in care due to neglect have the greatest number of medical problems.

On the basis of an analysis of the 1994 National Health Interview Survey-Disability Supplement (NHIS-DS), LaPlante and Carlson (1996) have estimated that 2 percent of the U.S. population has mental retardation or a developmental disability. This is known to be an underestimate, since these data do not include people in institutions, the correctional system, or the military. According to the Arc of the United States—an advocacy organization formerly called Association for Retarded Citizens of the United States—a review of a number of prevalence studies indicates that 2.5 to 3 percent of the general population has mental retardation or a developmental disability (Batshaw, 1997). Applying Batshaw's percentages to the 1990 census of the general population, the Arc of the United States estimates that 6 to 8 million people nationwide have mental retardation (Arc of the United States, 1998).

Definitions Vary

Because of the different definitions of disability, the population with disabilities is difficult to identify, and their victimization is difficult to measure. Different conceptual models have been proposed to understand disability in a variety of domains, especially health, education, and employment. Some of these explanatory paradigms describe disability as a personal problem caused directly by disease or trauma, and for which treatment or a

cure is required. In others it is viewed as occurring within a social context; that is, disability is a socially created problem and is in fact a matter of the full integration of individuals into society (World Health Organization, 2000).

The definition in the Crime Victims With Disabilities Awareness Act of 1998 appears comprehensive, but it is not characterized by the clarity and specification required for careful measurement. While the workshop discussion, in part, was organized around the statutory definition, that should not be taken to imply that research, especially the collection of prevalence and incidence data, should be driven by it. In her paper, workshop presenter Patricia Sullivan discusses disability under six categories or explanatory models to help account for differences in definition across the different domains discussed in the literature and embodied in the statutory definition. These categories include the medical model, the educational model, the legal model, the entitlement model, the cultural model, and the integrated model. They vary according to the services or needs of the individual seeking assistance for a particular disability, the needs of those collecting the information, and the estimates they produce of both disability and crime victimization.

These models are not mutually exclusive. For example, both the medical and legal model consider medical and psychiatric problems, and both the educational and medical models consider health-related educational difficulties. The models underscore the problems involved in developing clear definitions on which to base data collection and research efforts. The difficulty of defining disability presents a formidable barrier and challenge to measuring the nature and extent of violence and abuse committed against those with disabilities.

The Medical Model

The medical model of disability pertains to maternal and child health and is predicated on the need to provide some type of health care service to children with developmental disabilities. According to the Bureau of Maternal and Child Health's definition, "children with special health care needs" are children with health problems that require more than routine and basic health care, and they include "children with or at risk of disabilities, chronic illnesses and conditions and health-related education or behavioral problems." The definition also includes "children who have or are at increased risk for chronic physical, developmental, behavioral, or emo-