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Feasibility of expanding NEISS-AIP to create a scientific database on violence and disability

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Abstract

Background: This study identifies a feasible approach to an evidence-based source of information about violence and disability.

Objective: The purpose was to determine the feasibility of using the National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP) to collect data about violence and disability, by identifying intentional injuries of patients with disabilities in NEISS hospital emergency departments.

Methods: Protocols were developed for collecting information about essential variables on violence and disability, training of NEISS hospital coordinators and emergency department staff, and evaluating the procedures by NEISS hospital coordinators.

Ten NEISS hospital emergency departments were selected at random from the total of 64 NEISS hospitals. The protocols were applied in a data collection effort of 6 months. The data were weighted and sent to the researcher for further examination and analysis. Feasibility was determined by the evidence provided by the data collection and analysis and examination of the program evaluation questionnaire completed by each of the NEISS hospital coordinators.

Results: Inspection of the data and the evaluations completed by the NEISS hospital coordinators supported the feasibility of the study with a recommendation for more intense training to better categorize the type of disabilities in the future study population.

Conclusions: The utilization of NEISS-AIP for the purpose of developing a more scientific database on violence and disability with capability of providing national estimates is feasible. Based on this feasibility study, the researcher will move to the next stage of an expanded study. © 2011 Elsevier Inc. All rights reserved.

Keywords: Violence and disability; Intentional injury; Epidemiology of disability and violence; Abuse; Maltreatment; People with disabilities

This is a report of an investigation to determine the feasibility of expanding an existing data collection system, the National Electronic Injury Surveillance System—All Injury Program (NEISS-AIP). The intent is to create a scientific database about intentional injury against individuals with disabilities that can be extrapolated to the entire U.S. population for purposes of national public health planning and assessment of programs to prevent violence against this population.

In this article, a 6-month feasibility study is described to test NEISS-AIP for monitoring intentional injuries against children and adults with disabilities treated in emergency

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departments of U.S. hospitals. The researcher reports on the research design and methodology, the results and discussion of the findings of the study, and the evaluation of the feasibility of the proposed system.

Abuse, maltreatment, assaults, and other acts of violence against persons with disabilities result in long-term adverse effects on all aspects of life, including social, personal, and economic factors. These violent acts lead to injuries and chronic illnesses and have been identified as a public health issue of great concern and a hazard to the quality of life of individuals with disabilities. Persons with disabilities who are at greatest risk have types and severity of disability that limit their capacity for self-protection, such as (a) the ability to comprehend danger to self; (b) the ability to escape from the perpetrator; (c) the ability to fend off the perpetrator when physically assaulted; and (d) the ability to communicate to medical and legal authorities about the nature of the attack [1].

The need for a scientific, valid, and reliable database on the prevalence and incidence of abuse and acts of violence against children and adults with disabilities has been clearly identified. It was a major recommendation of a consensus of national leaders in violence prevention at the 2002 National Conference on Preventing and Intervening in Violence Against Children and Adults with Disabilities. The conference was sponsored and supported by 12 national agencies and organizations. Recommendations for research needs were made by researchers, advocates, consumers, and providers of services who attended the conference. These needs include, but are not limited to, learning the causes of violence, identifying the characteristics of perpetrators and their relationship to the victims, and developing efficient and cost-effective programs for violence prevention and intervention programs for persons with disabilities [2].

In 2007, the National Council on Disability and other advocacy organizations recommended that efforts be made "to engage in national research that will establish the prevalence and consequences" of crime against persons with disabilities [3, p. 3].

The existing information about prevalence of abuse and violence against persons with disabilities, although valuable, is based on small clinical studies, self-reports, telephone surveys, and a mix of methodologies. These efforts, however, impose serious limitations regarding the accuracy and interpretation of the data for national estimates. Despite the limitations, these studies have identified certain trends. For example, recent studies indicate that women with severe disabilities were 4 times more likely, compared to women without disabilities, to report being sexually abused [4]. A report in 2008 revealed that women with disabilities experienced almost twice the rate of all forms of abuse compared to the other populations [5]. In another study, researchers found that men with cognitive disabilities were more than twice as likely as their peers with other disabilities to report being physically assaulted by hitting, kicking, or slapping [6]. Sullivan and Knutson, in their study [7], found that children with disabilities are 3.4 times more likely to be maltreated than are their peers without disabilities. In 2001, Peterselia et al. [8] stated in their landmark report that violence against children with developmental disabilities is seriously underreported. As an example of underreporting, according to the Bureau of Justice Statistics (BJS) only 37% of all crimes committed were reported to the police [9]. Marge observed, therefore, that reported data about victimization should be considered "the tip of the iceberg [2, p. ii]."

In 2009, the BJS of the U.S. Department of Justice (DOJ) presented the first estimates of crimes against people with disabilities, aged 12 and older, as measured by the National Crime Victimization Survey (NCVS) [10]. The survey used mixed methodologies for data collection, including telephone surveys, police records, personal interviews, and proxy respondents, to provide prevalence rates. The crime victimization of persons with disabilities was compared to those without disabilities, using population estimates based on the U.S. Census Bureau's American Community Survey (ACS). The NCVS defined violent crimes as rape/sexual assault, robbery, aggravated assault,

and simple assault. It reported that 716,320 persons with disabilities were victimized compared with 4,432,460 persons without disabilities. Age-adjusted rate of nonfatal violent crime against persons with disabilities was 1.5 times higher than against those without disabilities. These statistics were translated into age/adjusted rates per 1,000 with 32.4 per 1,000 for victims with disabilities compared to 21.3 per 1,000 for victims without disabilities. More specifically, youth with disabilities experienced the highest rates of victimization with nearly twice the rate as those without disabilities (82% per 1,000 versus 43% per 1,000).

Authors of the 2009 Bureau of Justice Statistics Report (BJSR) cautioned that the data must be considered within the context of limitations. The first limitation was that 70% of the interviews were conducted by telephone. For people with disabilities who have communication disorders or use technology to enhance their ability to communicate, this approach could result in poor quality of the data collected. In addition, some of the complex concepts and the language of the questionnaire may not have been easily understood by people with cognitive disabilities. Furthermore, in cases where the respondent could not participate, proxies were used. It was difficult to determine whether the proxies truly understood the nature of the problems being questioned and/or could have been the perpetrator of the crime experienced by the respondent. Finally, since the NCVS is conducted by personal visit and telephone interviews and the ACS is a self-administered survey, possible bias may impact on the estimates and their comparisons. Despite these limitations, the BJSR provides the best current estimate of crimerelated victimization among persons, aged 12 and older, with and without disabilities. No data are available for children under the age of 12 years [10].

Limitations of current survey approaches

The use of telephone surveys that was once considered a most cost-effective and efficient approach for national surveys is now questionable. Krisberg (2009) stated "today, growing numbers of people have no landline at all, only a cell phone, and general assumptions about who will be at the other end of a phone call are quickly shifting" [11, p. 1,12].

Another concern is that information obtained by self-reports has been questioned. It is revealed that women report only "20% of all rapes" to the police and "25% of all physical assaults and 50% of all stalking perpetrated by intimate partners." But, the emergency department physician has been identified as "the first professional from whom an abused person seeks help." In fact, more than 85% of Americans indicated they could tell a physician if they had been a victim of family violence "more than their spiritual advisor and considerably more than law enforcement" [12].

Although these reported studies point to the extraordinary risk of those with disabilities for victimization by

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