

PREVALENCE OF MALTREATMENT OF PEOPLE WITH INTELLECTUAL DISABILITIES: A REVIEW OF RECENTLY PUBLISHED RESEARCH

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Maltreatment can have a profound adverse effect on the health of individuals with intellectual disabilities (ID). People with ID may also be more likely to experience maltreatment than other groups. Historically, data on prevalence of maltreatment among people with ID have been sparse and methodologically weak but have suggested that the scope of the problem is considerable. Studies published between 1995 and 2005 were reviewed to determine estimated maltreatment prevalence among people with ID based on recent literature. Prevalence estimates for people with ID were compared to estimates for people with no disabilities and people with other types of disabilities. Only five studies provided maltreatment prevalence estimates for people with ID. The limited data suggest that maltreatment is more prevalent for people with ID than for people with no disabilities and may be higher for people with ID than for people with certain other disabilities. Most of the available research is still based on convenience samples. More population-level data are needed to provide reliable estimates of the prevalence of this important health problem.

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MRDD Research Reviews 2006;12:57–69.

Key Words: maltreatment; prevalence; intellectual disability (mental retardation)

Maltreatment has been identified as a significant health issue for people with intellectual and other disabilities [Sobsey, 1994; Curry et al., 2001; USDHHS 2002]. Among the general population, exposure to maltreatment has been shown to produce a range of sequelae, including physical trauma, compromised psychological health, or death [Tjaden and Thoennes, 2000; Ireland, 2002]. In addition to these consequences, people with disabilities may develop secondary disabilities and/or suffer loss of independence [Mitchell and Buchele-Ash, 2000; Swedlund and Nosek, 2000]. For example, a person with an intellectual disability may develop emotional problems as a result of psychological maltreatment or develop a secondary mobility disability as a result of physical abuse.

Unfortunately, while maltreatment in the general population has been recognized as a national priority with large-scale efforts to measure the prevalence of maltreatment and violence (e.g., National Child Abuse and Neglect Data System (NCANDS); National Violence Against Women Survey), little attention has been devoted to collecting comprehensive data on maltreatment of people with disabilities. Although the most recent report based on NCANDS data included disability as a demographic category, the data are acknowledged to be underestimates [USDHHS, 2005]. The data that are provided are for

children with disabilities in general, with no information about specific types of disabilities.

A number of authors [Jaude and Diamond, 1985; Ammerman and Baladerian, 1993; Sobsey, 1994] have reported that individuals with disabilities are more likely to be maltreated than individuals without disabilities. Moreover, it has been asserted that individuals with intellectual disabilities (ID) are at especially high risk [Levy and Packman, 2004]. One oft-cited study [Cross et al., 1993] did not support this assertion, based on finding similar proportions of children with ID in maltreated and general population groups. However, the study relied on Department of Education data for children aged 6–17 years as a comparison group, whereas the maltreated group also included children between the ages of 1 and 6 years. Because ID is often not diagnosed until children reach school age, the proportion of children with ID in the comparison group should logically have been higher than in the group that also included younger children. Furthermore, the maltreated sample was drawn from cases substantiated by child protective service agencies, some of which did not include maltreatment cases in institutional settings. For these reasons, Cross et al.'s [1993] report may have underestimated the relationship between ID and maltreatment.

Regardless of the position espoused, statements about disability and maltreatment are typically based on research that is more than 10 years old and that was conducted using convenience samples. For example, one of the most widely cited sources in the field is the book *Violence and Abuse in the Lives of People with Disabilities* published in 1994. In this seminal review, Sobsey estimated that people with disabilities were at least twice as likely, and perhaps five or more times as likely, to be victimized as people without disabilities. Another frequently cited estimate is that children with disabilities are 4 to 10 times more likely to be maltreated than children without disabilities [Ammerman and Baladerian, 1993]. Such estimates have been repeated numerous times [Strickler, 2001; Sorensen, 2003] with little updated data. The continued reliance on Sobsey [1994] can

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Received 2 November 2005; Accepted 4 November 2005
Published online in Wiley InterScience (www.interscience.wiley.com).
DOI: 10.1002/mrdd.20097

be ascribed in large part to the comprehensive nature of his discussion of the issues and the breadth of literature reviewed, despite the increasing age of the research on which it is based.

A more recent review of criminal victimization of people with developmental disabilities [Petersilia, 2001] also drew heavily on studies published prior to 1994, suggesting limited growth in the published literature in recent years. Moreover, both Sobsey's and Petersilia's reviews noted the dearth of quality data available for establishing the scope of the problem. Lack of data is a significant stumbling block to effectively addressing maltreatment of people with ID and other developmental disabilities. As with any other threat to health, determining the extent of maltreatment—the proportion of the population that is affected—is a critical step in planning appropriate responses [Gordis, 2000]. Allocation of resources for prevention and treatment is based in part upon current data regarding the prevalence of a particular health problem [Pickett and Hanlon, 1990].

In order to strengthen understanding of the current state of knowledge, this paper examines research published since 1994 on the prevalence of maltreatment of people with intellectual disabilities. The review of this literature focuses on three questions:

1. What is the estimated prevalence of maltreatment among people with ID based on studies published in 1995 or later?
2. How do the prevalence estimates for people with ID differ from estimates for people without disabilities?
3. How do the prevalence estimates for people with ID differ from estimates for people with other types of disabilities?

KEY TERMS

The term “intellectual disability” is used in many countries to describe what has often been referred to in the United States as mental retardation, developmental disability (particularly intellectual limitations), or cognitive disability. It is also similar to the terms learning disability or learning difficulties as used in the United Kingdom, which are distinct from the U.S. use of learning disability as a condition that affects scholastic achievement (e.g., dyslexia) without necessarily implying limitations in overall intellectual functioning.

Maltreatment in the context of this review is any cruel or harmful behavior,

which may or may not also be considered a crime. Maltreatment may take a number of forms, including physical abuse, sexual abuse, verbal and psychological or emotional abuse, neglect, and financial exploitation. Although people with disabilities are subject to the same types of maltreatment as people without disabilities, having a disability can also put individuals at risk for unique forms of maltreatment related to their impairment or accommodation needs. For example, perpetrators may withhold adaptive mobility or communication devices as a way of controlling and isolating a person with a disability [Kaminker, 1997; Nosek et al., 1997].

This review focuses on prevalence of maltreatment among people with intellectual and other disabilities. The term *prevalence* refers to the proportion of persons affected with a particular condition

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in a specified population at a designated point in time [Gordis, 2000]. This proportion is typically expressed as a percentage. For the purposes of this paper, prevalence refers to the proportion of people with intellectual or other disabilities who, at the time data were collected, had experienced maltreatment at some point. Depending on the study, the maltreatment might have been experienced at any time during the individual's life thus far or during a shorter period such as the past year.

Prevalence is often confused with *incidence*, which refers to the number of new cases of a condition or experience occurring during a particular time period within a population at risk [Gordis, 2000]. Thus, incidence refers to the rate at which something occurs. In describing maltreatment, incidence focuses on numbers of new maltreatment events, while prevalence focuses on the proportion of people who have experienced maltreatment. A given individual could experience multiple episodes of maltreatment

within a given time period, which would be reflected in the incidence rate. While incidence studies provide important information about how frequently maltreatment occurs for people with disabilities, the focus of this paper is on examining the proportion of the population that has experienced maltreatment based on the available data.

METHOD

A search of MEDLINE (1986–2005), PsychINFO (1985–2005), and Cumulative Index to Nursing and Allied Health Literature (CINAHL, 1982–2005) databases was conducted to identify studies containing data on prevalence of maltreatment of people with intellectual or developmental disabilities. To be certain of capturing all potentially relevant studies, a broad range of disability-related search terms was used. These terms included multiple types of developmental disabilities and other disabilities in addition to intellectual disabilities. Specific disability search terms included the subject headings disabled persons (MEDLINE), disabilities (PsychINFO), disabled (CINAHL), mental retardation, child development disorders, fetal alcohol syndrome, spinal dysraphism, hydrocephalus, microcephaly, and muscular dystrophies, as well as keywords mental\$ or development\$ or learning or intellect\$ or cognit\$ disab\$ or handicap\$ or retard\$, Down syndrome, autism or autistic, epilepsy or epilept\$, and spina bifida. These were combined with maltreatment-related terms (crime, crime victims, maltreat\$, mistreat\$, neglect\$, exploit\$, physical\$ or sex or sexual\$ abus\$, and victim\$) and prevalence and data-related terms (morbidity and epidemiology). (\$) represents truncation for the search.)

Searches were limited to English language articles published from 1995 to July 2005. The searches were initially limited to studies of adults. However, as the resulting body of literature was quite small, and as some recent large-sample studies of children and youth with disabilities have made important contributions to the field, the searches were expanded to include all ages. The database searches yielded 261 citations in MEDLINE, 128 in PsychINFO, and 83 in CINAHL. There was some overlap between databases; 353 of the citations were unduplicated.

An initial screening of the abstracts resulted in 53 identified from the MEDLINE search as potentially containing data on prevalence of maltreatment among people with intellectual or other

Table 1. Characteristics of Studies that Included People with ID

Study	N	Age Group ^a			Maltreatment Type ^b							Prevalence Time Period ^c				Data Source ^d				Recruitment Context ^e				Sample Type ^f		Comparison Group ^g		
		C	Y	A	P	S	E	F	N	D	L	AL	Yr	SE	SR	M	Pr	CN	AD	Cm	Sc	Cl	I	Co	PB	OD	ND	NC
Beail and Warden [1995]	88		X	X		X					X							X				X		X				X
McCabe and Cummins [1996]	80				X	X					X				X					X				X			X	
Powers et al. [2002]	169			X		X	X	X	X	X	X				X					X				X		X		
Sullivan and Knutson [2000]	50,278	X	X			X	X	X		X	X								X			X			X	X	X	
Verdugo et al. [1995]	848	X	X			X	X	X		X	X						X						X	X				X

^aC, children; Y, youth; A, adult.

^bP, physical; S, sexual; E, emotional; F, financial; N, neglect; D, disability specific.

^cL, lifetime; AL, adult lifetime; Yr, past year; SE, specific event.

^dSR, self report; M, mother's report; Pr, professional assessment; CN, case notes; AD, administrative data.

^eCm, Community; Sc, school; Cl, clinic; I, institution.

^fCo, convenience; PB, population based.

^gOD, other disabilities; ND, no disabilities; NC, no comparison group.

disabilities. An additional 9 abstracts were kept from the PsychINFO search, and 3 more from the CINAHL search, for a total of 65 abstracts. A second, more detailed review resulted in a number of initially selected abstracts being rejected because they focused on people with intellectual or developmental disabilities as perpetrators of abuse or on risk factors for maltreatment rather than prevalence data. Based on this second screening of abstracts, 27 full articles were obtained.

In addition to the database searches, the reference sections of relevant articles selected from the above searches were scanned for additional studies published during the target time frame. Articles that were not themselves prevalence studies but that discussed maltreatment of people with disabilities and referenced prevalence studies were retrieved and their reference sections were scanned. An additional 11 studies were identified based on citations in other articles.

The 38 articles were read to determine whether they were relevant for inclusion in the review. Articles were selected as relevant if they contained prevalence data for a sample of people with disabilities (as opposed to disability within a maltreated sample), although in some cases it was not the primary focus of the article. Articles were excluded if they did not provide original data or if they presented data only on incidence and not on prevalence.

RESULTS

Eighteen studies were identified for inclusion in the literature review. Eight of the studies focused on maltreatment of children and adolescents and 10 studies focused on maltreatment of adults. One of the child and adolescent studies [Verdugo et al., 1995] focused

specifically on children with intellectual disabilities. Another study [Sullivan and Knutson, 2000] explicitly included children with ID as well as children with other disabilities. A third study [Blum et al., 2001] used criteria for identifying youth with learning disabilities (have difficulty with school work daily or nearly daily and receive special education) that could have included youth with ID. However, it is not clear whether students with ID participated in the written survey in order to be included in the sampling frame. Svetaz et al. [2000] studied youth with learning disabilities who were identified by their parents as having a learning disability and as ever having been in special education. The data were drawn from the same school-based survey as that used by Blum et al. [2001], which may not have included students with ID. The more specific focus on learning disabilities used by Svetaz et al. [2000] may have further reduced the possibility that youth with ID were included. Suris et al. [1996], Dawkins [1996], Little [2002], and Ebeling and Nurkka [2002] did not include children or youth with ID but did study other developmental disabilities.

Among the adult studies, two [Beail and Warden, 1995; McCabe and Cummins, 1996] exclusively studied individuals with ID. A third [Powers et al., 2002] explicitly included women with both physical and intellectual disabilities, as well as women with physical disabilities alone. Two studies [Matthias and Benjamin, 2003; Oktay and Tompkins, 2004] examined maltreatment perpetrated by personal assistants, and one [Bryen et al., 2003] studied maltreatment experienced by users of augmentative and alternative communication. Although these studies may have incidentally included individuals with ID, they

focused primarily on physical disabilities and were based on self-report surveys that may have precluded participation by people with significant cognitive impairments. The remaining four adult studies were of women with physical disabilities. Two of these studies [Young et al., 1997; McFarlane et al., 2001] required that participants have "no known cognitive impairments. . . that would significantly impair" ability to respond to survey or interview items.

For purposes of further characterizing the literature, the studies are divided into two categories: (1) those that studied individuals with ID exclusively or that explicitly included people with ID as well as people with other types of disabilities; and (2) those that focused on other types of disabilities and either excluded people with ID or are unlikely to have included substantial numbers of people with ID and did not examine them as a separate group.

Studies Including People with Intellectual Disabilities

Studies in this group are shown in Table 1. General characteristics of the studies are described below, followed by a summary of each study and its findings.

Study characteristics

Of the five studies, two focused exclusively on sexual abuse. One study was primarily about maltreatment from providers of personal assistance services but also examined physical and sexual abuse from other sources. The remaining two studies covered multiple forms of maltreatment, including neglect, emotional abuse, physical abuse, and sexual abuse. All five studies examined lifetime prevalence of maltreatment—whether an individual had ever experienced maltreatment.

One of the studies gathered data primarily through mail surveys. Another study utilized in-person interviews. A review of psychotherapy case notes was conducted in the third study. The fourth study surveyed professionals working with individuals with ID. The fifth study analyzed school records merged with databases of reported cases of child maltreatment.

Study contexts included four countries: Australia, England, Spain, and the United States. The Australian study used a community-based sample. The study conducted in England was based on clinic patients. The study conducted in Spain used an institutional sample. One of the U.S. studies used a community-based sample, while the other used a sample of children identified through school records.

The study designs represented in this body of literature ranged from small convenience samples to population-based epidemiological studies. One of the studies utilized a convenience sample with no comparison groups of people without disabilities or people with other (nonintellectual) disabilities. Two studies used convenience samples with comparison groups of people without disabilities. One study used a convenience sample with a comparison group of people with other disabilities. One study was population based and included a comparison group of people without disabilities as well as groups with other types of disabilities.

Summary of studies and findings

Beail and Warden [1995] reviewed case notes of 88 individuals with intellectual disabilities referred for treatment at a clinical psychology service in England over a 4-year period of time. The case notes were examined for any references to sexual abuse during the client's life. Sexual abuse was reported or disclosed in 22 (25%) of the cases.

McCabe and Cummins [1996] conducted guided interviews with 30 people with mild ID living in community houses and also surveyed a comparison group of 50 first-year psychology students. They found that 33% of the people with ID said they had experienced unwanted sexual contact compared to 23% of the students without disabilities. This difference was not statistically significant. The authors also tested sexual knowledge and found that the participants with ID in their study had a low level of knowledge of sexual abuse. Only 3% of these participants were able to cor-

rectly answer the question "What is sexual abuse?"

Powers et al. [2002] studied abuse among women using personal assistance services. Their sample included 169 women with physical disabilities, of whom 32 (16%) also had ID. The sample was recruited through Centers for Independent Living and disability agencies. Women in the sample completed a survey asking whether they had ever experienced various behaviors by personal assistance providers. Forty percent of the women said they had been insulted by personal assistants and 35.5% said their personal assistants had yelled or screamed at them. Financial abuse was another common issue, with 35.5% of the respondents saying their personal assistants stole money or items, 30% saying checks had been forged or credit misused, and 20% indicating that their personal assistants pressured them for money. Nineteen and a half percent of the women said their physical needs had been neglected, 14% had been physically abused, and 11% had been touched sexually in unwanted ways by personal assistants. Women with both ID and physical disabilities did not differ significantly from women with physical disabilities alone in the proportion of respondents who reported experiencing maltreatment from their personal assistants. Powers et al. [2002] also asked the respondents whether they had ever experienced physical or sexual abuse from anyone (not just personal assistants) during their lifetimes. Sixty-seven percent of the women said they had been physically abused, and 53% said they had been sexually abused. Again, there were no significant differences between women with ID and women with physical disabilities alone.

Verdugo et al. [1995] queried professionals about 445 children and youth, aged 0–19 years, with intellectual disabilities residing in three institutions in Castilla-León, Spain. The professionals working with the children and youth judged 11.5% of them to have experienced maltreatment based on behavior and physical evidence compared to 1.5% of a control group of 403 children and youth without disabilities.

Sullivan and Knutson [2000] utilized administrative records to compare maltreatment prevalence among children with and without disabilities. They merged school records containing disability information with records from social service and police victimization databases to identify children with a record of neglect or physical, sexual, or emotional abuse. The records showed that

31% of the children with disabilities had been maltreated compared to 9% of the children without disabilities. The authors also examined maltreatment prevalence by specific type of disability. Although precise percentages were not provided, a figure graphically depicting maltreatment prevalence for the different groups indicates that maltreatment was most prevalent among children with behavior disorders (approximately 53%), speech/language disorders (approximately 36%), mental retardation (approximately 28%), and health-related disabilities (approximately 28%). Maltreatment was also significantly more prevalent among children with hearing, physical, and visual disabilities than among children without disabilities. The only exception was children with autism, who did not have a significantly higher prevalence of maltreatment than children without disabilities.

Studies of People with Other Types of Disabilities

Because there were so few prevalence studies providing specific information about ID, studies of maltreatment and disability that did not clearly include people with ID were also reviewed. Only two of the ID studies provided comparisons to people with other types of disabilities. Therefore, the studies described below will be used to provide more information about maltreatment prevalence among people with other disabilities to better address the third research question. Studies of people with other disabilities are shown in Table 2. The general characteristics are summarized below. A description of each study and its findings follows.

Study characteristics

The types of maltreatment studied, and the operative definitions used, varied widely. Two studies focused exclusively on sexual abuse. Two studies were specifically about maltreatment from providers of personal assistance services. There were two studies of physical and emotional victimization of children with disabilities by their peers without disabilities. The remaining seven studies covered multiple forms of maltreatment, including neglect, emotional abuse, physical abuse, sexual abuse, financial exploitation, and disability-specific forms of maltreatment such as withholding needed equipment, medication, or assistance.

Five studies focused on lifetime prevalence of maltreatment. One study asked about maltreatment that had oc-

Table 2. Characteristics of Studies of People with Other Disabilities

Study	N	Age Group ^a			Maltreatment Type ^b							Prevalence Time Period ^c				Data Source ^d					Recruitment Context ^e				Sample Type ^f		Comparison Group ^g		
		C	Y	A	P	S	E	F	N	D	L	AL	Yr	SE	SR	M	Pr	CN	AD	Cm	Sc	Cl	I	Co	PB	OD	ND	NC	
Blum et al. [2001]	20,780		X				X							X	X						X				X	X	X		
Bryen et al. [2003]	40				X	X	X		X	X					X					X				X				X	
Dawkins, [1996]	103	X	X			X		X						X		X						X		X			X		
Ebeling and Nurkkala [2002]	41	X	X			X	X	X			X						X						X	X		X			
Little, [2002]	411	X	X			X		X					X			X				X				X				X	
Matthias and Benjamin [2003]	1,905				X	X	X	X	X	X			X		X					X					X			X	
McFarlane, [2001]	511				X	X	X				X		X		X							X		X				X	
Milberger, [2003]	177				X	X	X				X		X		X					X				X				X	
Nosek, [1995]	31				X	X	X	X			X				X					X				X				X	
Oktay and Tompkins [2004]	84				X	X	X	X	X	X			X	X					X				X				X		
Suris et al. [1996]	2,961		X				X				X				X						X				X	X	X		
Svetaz et al. [2000]	16,240		X			X	X						X		X						X				X		X		
Young et al. [1997]	846				X	X	X	X			X				X					X				X				X	

^aC, children; Y, youth; A, adult.

^bP, physical; S, sexual; E, emotional; F, financial; N, neglect; D, disability specific.

^cL, lifetime; AL, adult lifetime; Yr, past year; SE, specific event.

^dSR, self report; M, mother's report; Pr, professional assessment; CN, case notes; AD, administrative data.

^eCm, Community; Sc, school; Cl, clinic; I, institution.

^fCo, convenience; PB, population based.

^gOD, other disabilities; ND, no disabilities; NC, no comparison group.

curred since the respondent was 18 years old. One study asked about maltreatment ever committed by certain people. Five studies examined maltreatment that had occurred within the past year. Two studies used a specific event—intercourse before age 12—as a marker of sexual abuse (one of these also asked about violence experienced in the past year).

Data collection methods included telephone, mail, in-person, and online surveys, as well as medical record review and professional opinion. Eleven of the studies used self-report surveys or interviews of people with disabilities. One study conducted a survey of mothers of children with disabilities. One study was based on medical records and judgments of professionals working with individuals with disabilities.

This group of studies included one conducted in England and one in Finland. A third study included respondents from both Canada and the United States. The remaining 10 were based entirely on U.S. samples. One of the studies used an institutional sample. Three studies accessed participants through schools and two through clinics. Seven of the studies utilized community-based samples.

As with the studies that included people with ID, study designs in this group ranged from small convenience samples to large population-based samples. Seven studies utilized convenience samples with no comparison groups of people without disabilities or people with other disabilities. One study used a convenience sample with a comparison group of nondisabled individuals, and an-

other used convenience sampling and comparison groups of people with other types of disabilities. One study conducted population-based sampling with no comparison group. One study was population-based and included a comparison group with no disabilities. Two studies were population based and included comparison groups of people without disabilities and people with other disabilities.

Summary of studies and findings

Bryen et al. [2003] studied experiences of crime and abuse among U.S. and Canadian adults using augmentative and alternative communication (AAC), such as communication boards or speaking computers. Forty individuals were recruited through e-mails to AAC professionals and to subscribers of an online group of AAC users and allies. Surveys were conducted online or via e-mail. Bryen et al. [2003] stated that 45% of the respondents said they had experienced one or more types of crime or abuse in their lifetimes. However, details regarding specific types of maltreatment are presented for 21 respondents, which in fact constituted 52.5% of their sample. Prevalence for each type of maltreatment was presented by the authors as a percentage of the 21 respondents who had experienced maltreatment. For consistency with other results presented in this review, those percentages are multiplied by 52.5% (the percentage of the sample who experienced any maltreatment) to provide a proportion of the total sample experiencing each form of maltreatment.

Thus, 29.5% of the full sample had experienced theft and 20.5% had experienced physical attacks. Twenty and a half percent had been subjected to unwanted sexual touch, 11.6% had been forced to have sex, 8.9% had been forced to touch someone sexually, and 14.7% had been threatened with sexual assault or harm.

Four studies [Nosek, 1995; Young et al., 1997; McFarlane et al., 2001; Milberger et al., 2003] focused on prevalence of maltreatment among women with physical disabilities. Nosek [1995] described a qualitative study carried out by the Center for Research on Women with Disabilities (CROWD). Interviews were conducted with 31 women with physical disabilities recruited through personal contacts and by fliers distributed locally and nationally. Interview transcripts were examined for specific reports of physical, sexual, or emotional abuse experiences. In all, 25 of 31 women (nearly 81%) reported experiencing abuse. Nosek [1995] went on to describe the experiences of sexual abuse specifically, which were reported by 11 (35.5%) of the women.

CROWD continued to examine abuse experiences through a national survey of women with disabilities. In one of the rare adult prevalence studies to utilize a comparison group, Young et al. [1997] surveyed 504 women with disabilities recruited through Centers for Independent Living and media announcements and asked them to pass on a survey to a non-disabled female friend, resulting in a comparison group of 442 women without disabilities. About 62% of the women

in both groups reported that they had experienced some type of abuse at some point in their lives. Women with and without disabilities did not differ significantly in the proportions that had experienced emotional (51.7 versus 47.5%), physical (35.5 versus 35.6%), or sexual abuse (39.9 versus 37.1%), but women with disabilities had experienced abuse for significantly longer periods of time than women without disabilities.

McFarlane et al. [2001] conducted interviews, using a four-item abuse assessment screener, with 511 working age (18–64 years) female patients with physical disabilities recruited through specialty clinics. Rather than addressing lifetime prevalence of abuse, they asked specifically about abuse within the past year. Using this time frame, 7.8% of their sample reported physical or sexual abuse, and an additional 2% reported disability-specific abuse (prevention of assistive device use or refusal to meet personal care needs). Milberger et al. [2003] used the same questions as McFarlane et al. [2001] but altered the time frame to assess abuse experienced by women since the age of 18. Their sample included 177 Michigan women with physical disabilities recruited through disability organizations, domestic abuse organizations, and radio ads. Fifty-six percent of the women indicated a history of abuse.

Oktay and Tompkins [2004] conducted telephone interviews of individuals receiving personal assistance services. Their sample consisted of 84 Maryland respondents recruited through a local advocacy organization and a local chapter of a spinal cord injury organization. They asked respondents whether their primary personal assistant had ever engaged in certain behaviors and whether any other current personal assistant had ever engaged in these behaviors. Thirty percent of the respondents reported one or more types of maltreatment from their primary personal assistance provider, while 61% reported one or more types of maltreatment from other personal assistance providers. With regard to specific types of abuse, substantial proportions of the respondents had experienced verbal abuse from their primary personal assistant (18%) or other personal assistants (29%). Six percent had been neglected by their primary personal assistant and 26% had other personal assistants neglect their needs. Physical abuse was experienced at the hands of primary personal assistants (10%) and other personal assistants (9%). Three percent said their primary personal assistants had sexual abused them and 8% said they had been abused by other per-

sonal assistants. Theft and extortion by primary personal assistants were reported by 9 and 8% of the respondents, respectively, while 29 and 15% had experienced theft and extortion, respectively, from other personal assistants.

Matthias and Benjamin [2003] conducted telephone interviews of recipients of both consumer-directed (511 respondents) and professional agency-directed (584 respondents) in-home care in California. The sampling frame consisted of all individuals who had been in California's In-Home Supportive Services program for at least 6 months and who did not have severe cognitive impairments. The sampling frame was stratified by service model, age, and severity of disability. Within these strata, individuals were randomly selected for study participation. Interviews were conducted in English, Spanish, Cantonese, Mandarin, or Vietnamese. Respondents were asked about inappropriate and abusive behavior of personal assistants within the past 12 months. Among the recipients of care managed by professional agencies, 17.8% said their providers had neglected them within the past year, 6.4% said they were injured while their providers were assisting them, 6.1% said their providers had yelled at them, 5.3% suspected their providers of stealing from them, 3.3% said their providers had threatened them, 1.9% said their providers had pushed, shoved, or hurt them physically, and 1.9% said the provider had made sexual advances. A significantly smaller percentage of respondents receiving consumer-directed care said they had been neglected (9.2%) or stolen from (4.2%). However, respondents in this group were more likely to report that their providers had yelled at them (7.8%). The two groups did not differ significantly in the other categories of maltreatment.

Dawkins [1996] studied experiences of bullying among children with and without disabilities. Children attending a child development center were selected based on presence of disabilities that would be readily apparent to other children, including cerebral palsy (CP), muscular dystrophy, marked coordination disorders, polio, spina bifida, and Erb's palsy. Children with an intelligence quotient (IQ) below 70 or known to be attending a school for students with ID were excluded. A control group of children without visible disabilities was selected from patients at a general pediatric clinic. Both samples were stratified by age: 8–11 and 13–16 years. Children were sent a self-report questionnaire asking how frequently they were bullied at

school. Surveys from 57 children with disabilities and 46 children without disabilities were analyzed. Dawkins [1996] found that children with disabilities were significantly more likely to say they were being bullied. Half of the children with disabilities said they had been bullied at least once during the current school term compared to 21% of the children without disabilities. Thirty percent of the children with disabilities reported experiencing bullying on a regular basis, while 14% of the children without disabilities were bullied regularly.

Little [2002] conducted a nationwide survey of mothers of children (aged 4–17 years) with Asperger's syndrome (AS) or nonverbal learning disabilities (NLD). A convenience sample of survey participants was recruited through two websites for parents of children with NLD and AS. Fully 94% of the mothers reported that their children had experienced peer victimization during the past year in the form of emotional bullying, physical violence, and/or social exclusion. The survey did not include a comparison group of mothers of children without disabilities. However, Little [2002] compared her data to findings from national studies of peer victimization among children in general and noted that the prevalence of various forms of victimization reported by the mothers in her study was two to eight times higher than the proportions reported in the general population studies.

Ebeling and Nurkkala [2002] studied 41 children (aged 6–17 years) who were inpatients in a child psychiatric ward in Finland. Diagnoses included emotional disorders, behavioral disorders, psychotic disorders, and developmental disorders such as speech disorders, delays in scholastic skills, AS, and unspecified pervasive developmental disorders. The researchers studied both "active" violence committed against the child, and "passive" violence, in which children witnessed violence or were exposed to sexual materials. Staff reported that 88% of the sample had experienced or been exposed to physical, psychological, sexual, or chemical (exposure to drugs or alcohol) maltreatment. In fact, staff suspected maltreatment of all but one child. Sixty-six percent of the children had experienced "active" violence, and the remaining 22% had been exposed to "passive" violence alone. Among the 7 children categorized as having developmental disorders, staff judged 70% to have experienced maltreatment, all of which was classified as "active." This prevalence was not significantly different

Table 3. Results of Studies that Included People with ID

Study	People with ID (% maltreated)	People with Other Disabilities (% maltreated)	People with No Disabilities (% maltreated)
Beail and Warden [1995]	Sexual: 25	N/A	N/A
McCabe and Cummins [1996]	Sexual: 33	N/A	N/A
Powers et al. [2002] ^a	PA verbal (insults): 40 ^b PA verbal (yelling): 35.5 PA financial (theft) 35.5 PA financial (forgery) 30 PA financial (pressured for money) 20 PA Neglect: 19.5 PA Physical: 14 PA Sexual: 11 Anyone Physical: 67 Anyone Sexual: 53	PA verbal (insults): 40 PA verbal (yelling): 35.5 PA financial (theft) 35.5 PA financial (forgery) 30 PA financial (pressured for money) 20 PA Neglect: 19.5 PA Physical: 14 PA Sexual: 11 Anyone Physical: 67 Anyone Sexual: 53	N/A
Sullivan and Knutson [2000]	Any type: 28	Any type: 8–53	Any type: 9
Verdugo et al. [1995]	Any type: 11.5	N/A	Any type: 1.5

^aPowers et al. [2002] did not provide separate prevalence estimates by disability type.

^bPA, personal assistant.

from that found for the children with other types of disabilities.

Three studies consisted of analysis of large self-report studies of adolescents accessed through school systems. Suris et al. [1996] used data from the Minnesota Adolescent Health Survey, a school-based written survey that included questions about sexual abuse. The authors found no significant differences in history of sexual abuse for youth with visible disabilities (e.g., CP, muscular dystrophy) compared to controls. However, 4.1% of boys with nonvisible conditions such as diabetes, asthma, and seizure disorders indicated a history of sexual abuse compared to 0.8% of the boys in the control group. Girls with nonvisible conditions also had a significantly higher prevalence of sexual abuse than girls in the control group (24 versus 17%).

Svetaz et al. [2000] and Blum et al. [2001] both used data from the National Longitudinal Study of Adolescent Health (Add Health). Add Health is a multiwave study of adolescents in grades 7–12. Youth were identified through schools and were initially surveyed at school. A subsample of 20,780 youth subsequently agreed to participate in an in-depth interview at home, with a parent also participating in a brief interview about the youth. Svetaz et al. [2000] analyzed data from 16,340 adolescents with completed in-depth interview data from both the adolescent and a parent. Of this subsample, 1,603 had learning disabilities as determined from parents' indication that the adolescent had a learning disability and had been in special education classes at some point. A significantly higher proportion of youth with learning disabilities

had witnessed or been the victim of a violent act within the past year compared to youth without learning disabilities (1 versus 0.8% for boys; 0.7 versus 0.3% for girls). The proportion of youth reporting intercourse before age 12 was also significantly higher in youth with learning disabilities than in youth without learning disabilities (6.5 versus 5% for boys; 3 versus 1% for girls).

Blum et al. [2001] analyzed data from all 20,780 Add Health youth who completed in-depth interviews. They studied youth with emotional disabilities and mobility impairments in addition to youth with learning disabilities. Blum et al. [2001] also examined intercourse before age 12 as an indicator of sexual abuse and found that 4.9% of youth with emotional disabilities, 6.6% of youth with mobility impairments, and 5.2% of youth with learning disabilities had been sexually abused. All of these percentages were significantly higher than the 2.8% prevalence among youth with no disabilities.

Estimated Prevalence of Maltreatment for People with ID

As has been the case with earlier research, estimates of the prevalence of maltreatment among people with intellectual disabilities in recent studies cover a wide range (see Table 3). In the two studies with children and adolescents with ID, lifetime prevalence estimates for maltreatment ranged from 11.5 to roughly 28%. In the three studies that included adults with ID, lifetime prevalence of sexual abuse alone ranged from 25 to 53%. Only one adult study examined any other type of maltreatment; Powers et al. [2002] found a physical

abuse prevalence of 67% among women with physical and intellectual disabilities.

Prevalence for People with ID Compared to People with No Disabilities

Where comparisons to nondisabled groups were made, individuals with ID were typically more likely to have been maltreated than people without disabilities. In the study by Vergudo et al. [1995], the prevalence of maltreatment was 7.66 times higher for children with ID than for children with no disabilities. Sullivan and Knutson [2000] found a maltreatment prevalence among children with ID that was 3.1 times higher than the prevalence of maltreatment for children with no disabilities. Only McCabe and Cummins [1996] found a nonsignificant difference in prevalence of maltreatment between people with ID and people with no disabilities.

Prevalence for People with ID Compared to People with Other Disabilities

Two studies, one of children and one of adults, included comparisons of ID to one or more other types of disability. Sullivan and Knutson [2000] examined nine categories of disability, as well as children with no disabilities. Maltreatment was more prevalent among children with behavior disorders and speech/language disorders than among children with ID. Children with health-related disabilities (such as asthma or rheumatoid arthritis) had the same maltreatment prevalence as children with ID. Maltreatment was less prevalent among children with other types of disabilities (hearing,

Table 4. Results of Studies of People with Other Disabilities

Study	People with Disabilities (% maltreated)	People with No Disabilities (% maltreated)
Blum et al. [2001]	Sexual: 4.9–6.6	Sexual: 2.8
Bryen et al. [2003]	Theft: 29.5 Physical: 20.5 Sexual: 8.9–25 Any type: 45–52.5	N/A
Dawkins [1996]	Bullying: 50	Bullying: 21
Ebeling and Nurkkala [2002]	Any type: 70–100	N/A
Little [2002]	Bullying: 94	N/A
Matthias and Benjamin [2003]	Neglect: 9.2–17.8 Injury during assistance: 5.0–6.4 Verbal (yelling): 6.1–7.8 Threats: 3.0–3.3 Theft: 4.2–5.3 Physical: 1.9 Sexual: 1.9–2.4	N/A
McFarlane et al. [2001]	Physical/sexual: 7.8 Disability-related: 2	N/A
Milberger et al. [2003]	Any type: 56	N/A
Nosek [1995]	Sexual: 35.5 Any type: 81	N/A
Oktay and Tompkins [2004]	Neglect: 6–26 Verbal: 18–29 Theft: 9–29 Extortion: 8–15 Physical: 9–10 Sexual: 3–8 Any type (primary personal assistants): 30 Any type (other personal assistants): 61	N/A
Suris et al. [1996]	Sexual: 4.1 (boys); 24 (girls)	Sexual: 0.8 (boys); 17 (girls)
Svetaz et al. [2000]	Violence: 1 (boys); 0.7 (girls) Sexual: 3 (girls)	Violence: 0.8 (boys); 0.3 (girls) Sexual: 1 (girls)
Young et al. [1997]	Emotional: 51.7 Physical: 35.5 Sexual: 39.9 Any type: 62.0	Emotional: 47.5 Physical: 35.6 Sexual: 37.1 Any type: 62.2

learning, physical, and visual disabilities, and autism). The authors did not indicate whether the differences between disability groups were significant. Powers et al. [2002] did not find significant differences between women with and without ID among the women with physical disabilities in their sample.

Additional information on prevalence of maltreatment for people with other types of disabilities was gathered from the studies that did not include people with ID (see Table 4). Three studies of adults with physical or communication-related disabilities presented prevalence of sexual abuse separately from other types of abuse, providing a possible comparison for the findings of Beail and Warden [1995] and McCabe and Cummins [1996]. However, Bryen et al. [2003] reported data on sexual abuse among augmentative and alternative communication users in four separate categories: unwanted sexual touching, forced sex, forced to touch someone sexually, and threatened sexual assault. Because respondents may have experienced

more than one of these forms of sexual abuse, it is impossible to determine a total prevalence of sexual abuse for their sample from the data provided.

Other studies presented data in a format more parallel to the studies of individuals with ID. Nosek [1995] found that 35.5% of her sample had been sexually abused. Similarly, Young et al. [1997] found that 39.9% of a considerably larger sample of women had experienced sexual abuse. These percentages are not dramatically different from the 33% found for adults with ID by McCabe and Cummins [1996]. The lowest prevalence was in Beail and Warden's [1995] case note review, which indicated that 25% of a group of clients with intellectual disabilities had been sexually abused.

While McFarlane et al. [2001] and Milberger et al. [2003] studied sexual abuse as well as physical abuse and disability-specific forms of maltreatment, both articles presented prevalence of sexual abuse and physical abuse combined, with no information about prevalence of

either form separately. Because Beail and Warden [1995] and McCabe and Cummins [1996] only studied sexual abuse, no comparisons regarding prevalence of maltreatment can be made between the studies of individuals with ID and McFarlane et al. [2001] and Milberger et al.'s [2003] studies of women with physical disabilities.

The two studies besides Powers et al. [2002] that examined maltreatment by personal assistance providers each used a different time frame for assessing prevalence. While Powers et al. [2002] asked respondents whether they had ever in their lifetimes experienced certain problem behaviors from any personal assistants, Oktay and Tompkins [2004] asked whether any of the individual's *current* personal assistants had ever maltreated them, and Matthias and Benjamin [2003] asked about prevalence of maltreatment only within the past year.

Despite the more limited scope of the personal assistant maltreatment experiences studied by Oktay and Tompkins [2004], when the prevalence of people

reporting particular types of maltreatment from a primary personal assistance provider is added to the prevalence reporting the same type of maltreatment from any other personal assistance provider, the resulting total prevalence of maltreatment from current personal assistants is higher for some types of maltreatment than the figures presented by Powers et al. [2002]. Oktay and Tompkins found a total prevalence of verbal abuse from current personal assistants of 47% compared to a lifetime prevalence for verbal abuse from any personal assistants of 35.5% in the study by Powers et al.. Neglect was reported by 32% of Oktay and Tompkins' respondents, and 19.5% of the women surveyed by Powers et al. Prevalence of theft was more similar in the two studies: 38% [Oktay and Tompkins 2004] and 35.5% [Powers et al., 2002]. Similarly, a physical abuse prevalence of 19% was reported by Oktay and Tompkins and 14% by Powers et al. Both studies found a sexual abuse prevalence of 11%. No form of maltreatment was less prevalent in Oktay and Tompkins' study than in Powers et al.'s study.

Matthias and Benjamin [2003] used a larger sample and population-based sampling techniques. Because they assessed only maltreatment experienced during the past year, prevalence of any given type of maltreatment was considerably lower in their study than in the other studies of personal assistant abuse. Nevertheless, even within this circumscribed time frame, 9.2% of the respondents with consumer-directed care and 17.8% of the respondents of agency-directed care said their personal assistance providers had neglected their needs compared to the 19.5% lifetime prevalence found by Powers et al. [2002].

In the only study besides that of Verdugo et al. [1995] of institutionalized children, Ebeling and Nurkkala [2002] found high proportions (70–100%) of maltreatment among children and youth with emotional, behavioral, developmental, and psychotic disorders. These proportions are 6.1 to 8.7 times higher than the 11.5% prevalence found among institutionalized children with ID by Verdugo et al. [1995]. In contrast, population-based studies of junior high and high school youth found relatively low proportions of participants self-reporting violence or sexual abuse. This was especially true for Blum et al. [2001] and Svetaz et al. [2000], who relied on intercourse before age 12 as their sole indicator of sexual abuse.

Suris et al. [1996] examined lifetime prevalence of any type of sexual

abuse, making their data somewhat more comparable to those of Sullivan and Knutson [2000]. Although Suris et al. used self-report data and Sullivan and Knutson analyzed administrative records of confirmed maltreatment, both drew on population-based samples of school children. Suris et al. found that the proportion of boys who said they had experienced sexual abuse was 5.1 times higher for boys with nonvisible disabilities than for boys with no disabilities. Among girls, the proportion with nonvisible disabilities who said they had been sexually abused was 1.4 times higher than the proportion of girls in the control group who indicated a history of sexual abuse. Sullivan and Knutson did not provide separate estimates for girls and boys but did find that children and youth with ID were four times more likely to have been sexually abused than children and youth

Only five studies were found that focused on or clearly included individuals with ID and were published in 1995 or later. Based on these five studies, maltreatment prevalence estimates are widely varied.

with no disabilities. To put this comparison with the findings of Suris et al. [1996] in context, Sullivan and Knutson [2000] found that children and youth with health impairments (roughly corresponding to the nonvisible disability category used by Suris et al.) were two times more likely to be sexually abused than children and youth with no disabilities.

Dawkins [1996] and Little [2002] found bullying by peers without disabilities to be a substantial problem for children and youth with certain types of disabilities. Unfortunately, no studies examined bullying of youth with intellectual disabilities. Thus, there are no data available on the proportion of children with ID who experience this type of maltreatment to compare with the prevalence found among children with other disabilities.

DISCUSSION

The purpose of this review was to examine studies on prevalence of maltreatment of people with ID published since 1994. These studies were reviewed to determine the current state of knowledge regarding estimates of maltreatment prevalence for people with ID and how these estimates compare to maltreatment prevalence estimates for people with no disabilities and people with other types of disabilities.

Estimating Prevalence of Maltreatment

Only five studies were found that focused on or clearly included individuals with ID and were published in 1995 or later. Based on these five studies, maltreatment prevalence estimates are widely varied. For the most part, these studies are based on convenience samples. As such, they provide prevalence for their particular samples with little ability to generalize to larger populations. Thus, our state of knowledge regarding the proportion of people with ID who experience maltreatment has advanced relatively little in the past decade.

Sullivan and Knutson's [2000] population-based study is the exception within this small body of literature, demonstrating the applicability of data-merging techniques to addressing this important topic. As computerized databases, record-matching strategies, and analysis of administrative data grow more widespread and more sophisticated, such techniques hold promise for providing a stronger empirical basis for the disability and maltreatment field. The strengths of administrative data should be balanced with the recognition that they only include officially reported cases of maltreatment, which may underestimate actual maltreatment prevalence to a greater extent for children with disabilities than for children without disabilities [Sobsey, 1994; Watson-Armstrong et al., 1999; Anonymous, 2001; Petersilia, 2001]. Nonetheless, Sullivan and Knutson's [2000] study was the only one that truly used an epidemiological design appropriate for determining population-level prevalence. The population-based sampling method, substantial sample size, and internal comparison groups set a standard that subsequent research in this field should strive to meet.

Comparing People with ID to People with No Disabilities

Despite the overall limitations of the current literature, it does continue to indicate the prevalence of maltreatment

is higher among people with ID than among people with no disabilities. Although one of the three studies that compared people with ID to people without disabilities found no statistically significant differences [McCabe and Cummins, 1996], this was likely due to their small sample size of 30 people with ID and 50 people without. The proportion of people with ID in the sample who said they had been sexually abused was 1.4 times higher than the proportion of people without disabilities who had been abused—a meaningful difference that would probably be statistically significant in a study with greater power. Unfortunately, the small sample size also calls into question the representativeness of the samples to their respective populations.

McCabe and Cummins' [1996] study was the only one comparing adults with ID to adults with no disabilities. The studies of children and youth with ID that included comparisons to nondisabled children and youth [Verdugo et al., 1995; Sullivan and Knutson, 2000] found that maltreatment was 3.1 to 7.66 times more prevalent among individuals with ID. These data are roughly consistent with Sobsey's [1994] estimate that people with disabilities are two to five times more likely to be maltreated than people without disabilities and also overlap with Ammerman and Baladerian's [1993] estimate that children with disabilities are at 4 to 10 times greater risk than children without disabilities.

Comparing People with ID to People with Other Disabilities

With regard to maltreatment prevalence for people with ID compared to people with other disabilities, the data are even more limited. Sullivan and Knutson's [2000] results suggest that maltreatment is more prevalent among individuals with ID than it is for several other types of disabilities. Although the ID group did not have the highest maltreatment prevalence, it was in the top half of the groups studied. Significance levels were not presented for differences between disability groups. Powers et al. [2002] found no significant differences between women with and without ID in a sample of women with physical disabilities. However, the sample of women with ID was quite small ($n = 32$), which may have resulted in insufficient power to detect a difference between the groups. In other words, a meaningful difference could exist even though it did not reach statistical significance in this study. Unfortunately, prevalence was not

presented separately for women with and without intellectual disabilities.

Studies of maltreatment prevalence among people with other types of disabilities were reviewed to provide additional comparisons to prevalence estimates in studies that included people with intellectual disabilities. Unfortunately, while slightly larger, the body of research pertaining to other types of disabilities is equally varied methodologically and in the manner in which data are reported, making comparisons across studies highly problematic. For example, the studies of sexual abuse among adults with ID reported lower proportions of maltreatment than the studies of adults with physical disabilities. However, the studies of individuals with physical disabilities focused exclusively on women, while the studies of people with ID included both men and women. Sexual

Despite the overall limitations of the current literature, it does continue to indicate that prevalence of maltreatment is higher among people with ID than among people with no disabilities.

abuse is typically reported to be more prevalent among females than among males [Finkelhor et al., 1990; Sedlack and Broadhurst, 1996; Tjaden and Thoennes, 2000]. Thus, the lower prevalence of sexual abuse in the ID studies may well be due to the inclusion of men rather than the type of disability. Additionally, the case note review conducted by Beil and Warden [1995], which found the lowest prevalence of sexual abuse, relied on voluntary disclosure of sexual abuse experiences by the individuals with ID or on reports made by others. The people with ID were not specifically surveyed or interviewed about abuse experiences as in the other studies.

In studies of personal assistant maltreatment, the results of Matthias and Benjamin [2003] and Oktay and Tompkins [2004] provide some indication that this type of maltreatment may be even

more prevalent than Powers et al. [2002] found either for women with both ID and physical disabilities or for women with physical disabilities alone. However, it is difficult to compare these studies given the different sampling methodologies utilized and the fact that Powers et al. [2002] studied lifetime prevalence of maltreatment from any personal assistants, while Oktay and Tompkins studied maltreatment from current personal assistants, and Matthias and Benjamin studied personal assistant maltreatment that had occurred within the past year.

Among institutionalized children with disabilities, Ebeling and Nurkkala [2002] found maltreatment to be much more prevalent in their sample of individuals with emotional, behavioral, developmental (other than ID), and psychotic disorders than Verdugo et al. [1995] found in their sample of individuals with ID. However, Verdugo et al.'s estimates were low compared to other studies' estimates of maltreatment among people with ID. Their identified prevalence of maltreatment in the comparison group without disabilities was also low (1.5%) relative to estimates for nondisabled children in other studies (e.g., 9% in Sullivan and Knutson [2000]). Conversely, Ebeling and Nurkkala's [2002] estimates were higher than those in most other studies. Their sample consisted of inpatients in a child psychiatric hospital. It is possible that at least some of the individuals studied had experienced maltreatment that led to problems resulting in their hospitalization. In other words, the very reason the individuals studied were in the sample to begin with may have been confounded with the variable of interest. Comparison between the two studies is further complicated by the fact that they were conducted in different countries. Cultural and legal differences between Finland and Spain may have influenced identification of disability, institutional norms, and/or maltreatment assessment. Similarly, caution is warranted in comparing either of these studies to others in this primarily U.S.-based body of literature.

Among noninstitutionalized youth with disabilities, the school-based self-report data analyzed by Suris et al. [1996] are juxtaposed to the administrative data analyzed by Sullivan and Knutson [2000]. One might expect the prevalence estimates to be higher in the self-report study than in the study examining reported and confirmed cases of maltreatment. However, in addition to the contrasting data sources, comparisons are once again hampered by differences in

data presentation. For example, Suris et al. provided separate prevalence estimates for girls and boys, while Sullivan and Knutson did not.

In general, the studies of maltreatment prevalence among people with disabilities vary so greatly in sample selection, study methodology, types and definitions of maltreatment, and presentation of data that comparison of one study to another results in more questions than answers. Furthermore, it is difficult to state with any confidence what proportion of people in any given disability group have experienced maltreatment. Thus, comparing maltreatment prevalence for people with ID to people with other disabilities remains an exercise in extrapolations and caveats.

Reflections and Recommendations

Given the paucity of recently published studies on the prevalence of maltreatment among people with ID, it is not surprising that the field continues to rely primarily on older studies and on unpublished data. There is currently little other choice. Aside from Sullivan and Knutson [2000], the few recent studies that do exist have continued earlier tendencies to rely primarily on convenience samples. We still have very few solid data on which to base maltreatment prevalence estimates for the total population of people with ID. This is especially true for adults with ID, for whom no population-based data on maltreatment were found in the literature search conducted for this review.

Although considerably more data are needed, the studies reviewed for this paper must be placed in the larger context of other studies related to the topic. For example, several recent studies [Sobsey et al., 1997; Sullivan and Knutson, 1998; Randall et al., 2001; Stermac et al., 2004] have examined samples of maltreated individuals and determined that relatively high proportions have intellectual or other disabilities compared to proportions of people with disabilities in nonmaltreated groups. While these studies do not enable estimates of the proportion of people with ID who experience maltreatment, they provide valuable information regarding the strength of the association between disability and maltreatment. Other studies [Doren et al., 1996; McCartney and Campbell, 1998] have examined individual and environmental predictors of maltreatment, thereby elucidating points at which interventions are most critical. Still others [Lumley et al., 1998; Miltenberger et al., 1999; Khemka and Hickson, 2000;

Khemka et al., 2005] have focused on evaluating prevention efforts. In addition to research studies, a number of publications [Goldson, 1998; Waldman et al., 1999; Anonymous, 2001; Ryan et al., 2001] have continued efforts to raise awareness of the problem.

There is also ongoing work related to ID and maltreatment that has not been published in traditional academic sources. While this review focused on articles published in peer-reviewed journals, additional information is available on the Internet [Petersilia, 2001], through conferences, and in unpublished papers. Nevertheless, the literature as a whole remains small, with a handful of key researchers bearing responsibility for much of the work. Continued emphasis is needed on the importance of the issue, with particular attention to bringing new researchers into the field.

... the prevalence of maltreatment may be higher for people with intellectual disabilities than certain other types of disabilities, although the recent research in this area is extremely limited.

It is important for researchers to learn more about the prevalence of maltreatment of people with ID and to make this information widely available. This may involve identifying more effective ways of collecting maltreatment data from or about people with ID. Some of the studies reviewed stated that people with ID were not included due to concerns about their ability to answer survey questions. Such issues should be considered carefully and alternative means of participation employed whenever possible to ensure the inclusion of people with ID in these critical research efforts.

In particular, more population-based data are needed. Such data could be collected through broad-based health surveillance strategies similar to those used to track other major health risks. Some modification will be needed if self-report data from people with ID are to be collected. For example, surveillance data are often obtained via lengthy, complex

telephone interviews. To facilitate participation of people with ID, interviews would need to be short and focused, with simple questions, clear response options, and explanations of all terms. Attention to the safety of respondents who might be experiencing maltreatment would require ensuring that possible perpetrators are not able to hear the interview as it occurs. Professional interviewers could adopt the needed changes with a modicum of additional training. While such a strategy may require a modest increase in resources initially, it will be a worthwhile investment in the health of a population whose needs are too often overlooked.

In the meantime, the data that are currently available indicate that the problem is substantial and needs to be addressed programmatically. Because maltreatment has such serious consequences for the physical and mental health of individuals who experience it, preventing and responding to maltreatment should be a priority in promoting and maintaining the health of people with ID. Health educators need to be aware of maltreatment as a major health issue for people with ID and provide training to help individuals protect themselves [Drum et al., 2000; Center for Opportunities and Outcomes for People with Disabilities, 2002; Oschwald et al., 2002]. Disability service providers can serve as another avenue for providing information about maltreatment to people with disabilities, particularly people with ID who may have less access to information through other channels. Training for law enforcement and legal personnel [Fitzsimons-Cova and Rothbart Seidman, 2001] is also important to help the legal community better respond to reports of criminal maltreatment and to interact more effectively with people with ID, including making needed accommodations to facilitate testimony [Dooley and Wood, 1993; Rogers, 1999]. Moreover, continued efforts to address the underlying contributors to maltreatment, such as negative attitudes toward people with ID and other disabilities [Sobsey, 1994; Watson-Armstrong et al., 1999], are essential.

CONCLUSION

To the extent that data are available, this review of recently published research supports previously published assertions that people with intellectual disabilities are more likely to experience maltreatment than people without disabilities. There is also some evidence that the prevalence of maltreatment may be

higher for people with intellectual disabilities than certain other types of disabilities, although the recent research in this area is extremely limited, and high-quality, generalizable data are even more scarce. Research enabling estimates of prevalence at the population level is still minimal. There is a clear need for more population-level data to better define the scope of the problem in order to more effectively allocate resources to address it. ■

ACKNOWLEDGMENT

The authors thank Andrew Hamilton for assistance with literature searches, Elizabeth Adams and an anonymous reviewer for helpful comments on earlier versions of the paper, and Susan Wingenfeld for compiling references and preparing the manuscript for submission.

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