

**National Adult Protective Services  
Technical Assistance Resource Center**  
Contract Number HHSP233201500042I

**REVIEW OF LITERATURE  
ON THE MALTREATMENT OF ADULTS WITH DISABILITIES**

Prepared for:  
Administration for Community Living  
Office of Elder Justice and Adult Protective Services  
Washington, DC 20201

Prepared by:  
WRMA, Inc.  
Rockville, MD 20852

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## I. INTRODUCTION

Under the contract for Solicitation 15-233-SOL-00643, WRMA, Inc., the contractor for the National Adult Protective Services Technical Assistance Resource Center (APS TARC), was charged with developing evaluation plans for both adult protective services (APS) programs overall and APS interventions, which respond specifically to the needs of adults with disabilities who have been mistreated. In an early planning meeting, the Administration for Community Living (ACL) and WRMA agreed that one evaluation plan could meet the requirements for both tasks.

WRMA prepared an evaluation plan comprised of three components:

- Component 1: Establish the APS Policy Framework and Review Literature on APS Interventions for Adults with Disabilities
- Component 2: Inventory of State Practices and Service Innovations
- Component 3: Understand APS Outcomes in a State Context

The evaluation plan required a report on the results of Component 1 at the end of the Option Year 1 (OY1). This report provides the review of literature on APS interventions for adults with disabilities. The policy profiles are provided in separate report.

With the guidance of ACL, the APS TARC team reviewed research on the maltreatment of adults with disabilities. Several resources were used to identify references, which would be useful for practitioners, administrators, researchers, and policy makers. These included MedLine (a bibliographic database service of the U.S. National Library of Medicine), EBSCO Information Services (a commercial academic journal information service), the National Center on Elder Abuse, libraries at University of Southern California and New York University, and Google Search.

Multiple search words were used in various combinations. Search words included, but were not limited to, the following: persons with disabilities, adults with disabilities, adults with intellectual disabilities, adults with physical disabilities, Deaf persons, maltreatment, abuse, neglect, interpersonal violence, intimate partner violence, sexual abuse, self-neglect, safety, protection, APS services, chronic mental illness, guardianship, research, statistics, services, national associations, etc. We excluded documents on the policies and practices of state and local APS agencies, as these topics are being reviewed under other activities of the APS TARC.

More than 120 articles were retrieved and reviewed to determine their relevancy. Many articles discussed protection or abuse of adults in general and did not discuss the population of persons with disabilities. Of the literature that discussed persons with disabilities, some pertained only to children and others only to adults older than 64 years of age. Many did not discuss maltreatment but were included for further review because they discussed the vulnerabilities of the population, which might reflect a risk for abuse. We excluded literature on abuse in institutions or literature that pertained solely to perpetrators of abuse.

We focused primarily on adults with disabilities, aged 18-64 years, and living in non-institutional settings in the United States. We examined the literature published within the past 20 years. We reviewed in depth more than 30 articles. Articles were classified into the following four topics: background population statistics, maltreatment of adults with disabilities, related risk factors, and service responses. Some articles discussed more than one topic. The number of articles that discuss each topic is indicated below.

- Population statistics [5]
- Maltreatment [12]
- Risk factors [11]
- Service responses [14]

This literature review is organized into sections addressing each of the above listed topics. Each article is summarized for the reader, and each section concludes with a summary of major points of interest for practitioners, researchers, administrators, and policy makers.

## **II. POPULATION STATISTICS**

To understand the potential magnitude of the problem, we discuss some basic statistics in the United States. As of 2015, the national estimate of all persons with disabilities, who were not living in institutional settings, was 40 million persons, of which approximately 20 million persons were adults between the ages of 18–64 years (US Census Bureau, *n.d.a*).

The Census Bureau fields the American Community Survey (ACS) from which most of the relevant population data are obtained. The types of disabilities collected by the ACS include: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, with a self-care difficulty, and with an independent living difficulty. National estimates of persons age 18–64 years for each type of disability are provided below. (Estimates are for each type of disability and persons may have more than one disability.)

- Hearing difficulty: 3,969,691
- Vision difficulty: 3,788,786
- Cognitive difficulty: 8,750,935
- Ambulatory difficulty: 10,092,267
- With self-care difficulty: 3,650,483
- With independent living difficulty: 6,910,449

The number of adults aged 35–64 years of age with disabilities is more than three and a half times greater than for the group of adults 18–34 years of age.

**Exhibit 1 Sex by Age by Disability Status, ACS 2015 Estimates**  
(U.S. Census Bureau, *n.d.c*)

	18-34 years	35-64 years	Total
Male with a Disability	2,291,851	7,689,529	9,981,380
Female with a Disability	1,927,123	8,077,085	10,004,208
<b>Total</b>	<b>4,218,974</b>	<b>15,766,614</b>	<b>19,985,588</b>

Estimates regarding the economic characteristics of the U.S. population aged 16 and older with a disability compared to those without a disability indicate some specific differences:

- Nearly three-quarters of persons with a disability (73.9%) were not in the labor force compared to less than a third of the those without a disability (29.5%).
- Persons with a disability were more likely to have had less than or a high school diploma (56.5%) than some college or a bachelors or higher degree (43.5%) compared to those without a disability (36.7% and 63.3%).
- Furthermore, persons with a disability were more likely to be below 100% of poverty (20.5%) compared to those without a disability (11.8%) (U.S. Census Bureau, *n.d.b*).

The Bureau of Justice Statistics has reported that rates of violent victimization for adults with disabilities between 2011 and 2015 ranged from 83.4 per thousand (persons 20-24 years of age) to 31.2 per thousand (persons aged 50-64) compared to 29.6 and 12.7 for the same age groups of persons without a disability (U.S. Department of Justice, 2017).

### **Relevance for Practice and Research**

Approximately 20 million adults aged 18-64 with disabilities reside in the United States. This is slightly less than 10% of the adult population of this age range.

- The socio-economic and educational status of these persons indicates that social service programs need to be familiar with and work closely with other service programs to fully address the needs of those who experience maltreatment.
- Future national surveys and data reports from the National Adult Maltreatment Reporting System (NAMRS) may supplement Census Bureau and Department of Justice reporting on persons with disabilities.

## **III. MALTREATMENT OF PERSONS WITH DISABILITIES**

The recognition of abuse of persons with disabilities, especially those with intellectual and behavioral disabilities, has had a long history in the United States. Most of the concern has been with the abuse of persons in institutions, which led to the widespread deinstitutionalization movement of both children and adults in the 1970s. With the integration of persons with disabilities into communities, there was less attention to potential abuse, as many persons lived in family settings. Nevertheless, there is a growing concern as to various forms of abuse of adults with disabilities, as well as, older citizens. In this section we review the literature on abuse

of persons with disabilities, including the literature that compares findings about persons with disabilities, and those without.

Balderian, Coleman, and Stream (2013) conducted an online survey that received 7,289 responses from a convenience sample of persons with disabilities and those who live or interact with them. Most respondents were between the ages of 41-60 years, but victims could include children with disabilities. This sample reported high percentages of persons with disabilities being abused over their lifetime.

- Approximately 70% of persons with disabilities reported that they had experienced abuse during their lives.
- Respondents could indicate more than one type of abuse and 87% reported having experienced verbal emotional abuse, 50.6% experienced physical abuse, 41.6% experienced sexual abuse, 37.3% experienced neglect, and 31.5% experienced financial abuse.
- Approximately a third (37.3%) said they had reported the abuse to an authority. The finding that only a third had reported the abuse to an authority is important to the understanding that the incidence of abuse, as known to social service agencies, is likely to be an undercount of abuse experienced by persons with disabilities.

Platt, Powers, Leotti, Hughes, Robinson-Whelen, et al. (2017) studied interpersonal violence using a convenience sample of 350 adults with disabilities. The mean age was 38.6 years. High rates of abuse were reported, such as more than two-thirds reported being abused as an adult. Some gender differences were observed, such as women reported experiencing sexual abuse almost three times more often than men, and more women than men reported financial exploitation. There were no differences for physical abuse and neglect.

The authors reported that “By and large our study demonstrated similarities rather than differences between men and women... This striking picture of gender similarities among study participants underscores the importance of reconsidering issues of gender among people with disabilities” (Platt et al., 2017, pp. 118-119). They suggested that neither gender nor disability alone determine the existence or outcomes of violence and that additional factors should be examined to further understand risk. Such factors include the following:

- Dependence on others
- Lack of accessible services
- Beliefs of abusers that abuse will not be reported or believed
- Exposure to new settings in which abuse can occur

Roberto and Teaster (2005) examined cases of 142 women found by adult protective services (APS) to have been abused. The authors compared women in the following age groups, 18-39 years, 40-59 years, 60-79 years, and 80 years and older. Types of disability were not reported, except as to whether the victim was not ambulatory. Some of their findings were as follows:

- Seventeen percent of all victims reported rape, and this was more often experienced by women ages 18-39 than the other age groups.

- Younger victims of sexual abuse (18-39 years and 40-59 years) were more likely to be socially engaged or oriented towards others than older victims.
- The youngest group (18-39 years) was more likely to be living in the community than other women. In general, location of abuse was associated with living arrangement.
- Women who were abused in the community were more likely to need assistance to manage their finances than women who were abused in other living arrangements.

Powers, Curry, Oschwald, and Maley (2002) conducted a survey of 200 women with physical disabilities or physical and cognitive disabilities, who used personal assistance services (PAS) providers. They included questions on life time experiences of abuse. Analyses indicated the following:

- During their lifetime, 67% of the women experienced physical abuse and 53% of the women experienced sexual abuse.
- PAS behaviors that were identified as hurtful with an incidence rate of more than 20% of respondents included stealing money or personal items, forging checks or credit cards, threatening physical harm, being drunk or high on the job, insulting remarks or yelling and screaming, making decisions without being asked, snooping, denying choice, ignoring request, and handling roughly.
- Impediments to managing PAS including low wages, lack of knowledge of additional resources, shortage of qualified providers, fear of provider backlash, and embarrassment of complaining.

Powers, Curry, McNeff, Saxton, Powers, and Oschwald (2008) conducted a survey of 342 men with physical disabilities, or physical and cognitive disabilities. The survey was similar to the one conducted on women and, based on an earlier number of focus groups, conducted with 76 men with disabilities who used PAS (Saxton, McNeff, Powers, Curry, Limont, et. al., 2006).

- Of those men who had been physically abused or sexually abused, about half of them had been abused since becoming disabled.
- In the past year 8.5% had been physically abused; 2.5% had been sexually abused.
- Abuse by PAS included poor job performance, verbal abuse, restricting or controlling life, rough handling, violating privacy, and financial abuse.
- Lifetime proportions of abuse included 11% reporting PAS provider physical abuse compared to 65% reporting physical abuse by anyone. Nine percent of men reported PAS provider sexual abuse compared to 24% reporting sexual abuse by anyone.
- Men who had a cognitive disability were more likely to experience abuse than men with only a physical disability.
- Men who had been born with a disability were more likely to experience abuse than men who acquired a disability later in life. Single, divorced, or widowed men were more likely to report being abused than men with partners.

Researchers have also examined whether rates of abuse are higher for adults with disabilities than for persons without disabilities. In general, women with disabilities were found to have

experienced more lifetime abuse than women without disabilities. Variations from this general finding have also been reported. Researchers have also been trying to determine the influence of race, gender, age, type of disability, social and economic status on the type of abuse, but many studies have been too small to fully test all hypotheses.

Nosek et al. (1997) compared a convenience sample of women aged 18-65 with physical disabilities without known mental health problems, who were living in independent living facilities (n=439), and women without disabilities (n=421) who were friends of persons with disabilities. The women with disabilities included those with spinal cord injury, polio, muscular dystrophy, cerebral palsy, multiple sclerosis, and joint and connective disorders. Approximately a quarter (24.2%) had severe disabilities.

Proportions of women with disabilities compared to women without disabilities did not vary on some features of abuse.

- Prevalence of abuse for women with disabilities compared to women without disabilities was 62.0% and 62.2%.
- Percentages of women experiencing specific types of abuse were also similar: emotional abuse (51.7% compared to 47.5%), physical abuse (35.5% compared to 35.6%), sexual abuse (39.9% compared to 37.1%).

Variations were found on other features.

- Women with disabilities were more likely to experience sexual abuse by attendants (1.6%) than women without disabilities (0%) or physical abuse by attendants (2.3% or 0.5%).
- Women with disabilities experienced abuse for significantly longer periods of time than women without disabilities (7.4 years compared to 5.6 years).

Nosek, Howland, Rintala, Young and Chanpong (2001) reported that although many types of abuse were similar to those of the general population, women with disabilities were also abused by withholding orthotic equipment, medications, transportation, or essential assistance with personal tasks. Based on studies examined by the National Study of Women with Physical Disabilities, they concluded:

- Research on domestic violence and sexual assault often did not examine the issue of disabilities.
- The system of disability related services was often not familiar with issues of abuse.
- “It is difficult to separate the effects of disability from the effects of poverty, low self-esteem, and family background in identifying the precursors to violence against this population” (p. 27).
- Girls and women with disabilities must be trained to understand inappropriate touching and to recognize abusive situations in the family or community.

A recent Bureau of Justice report using reports made to law enforcement found that persons with disabilities are more likely to be victimized than persons without a disability. The population

being compared was of persons 12 years or older during 2011–2015 and was not restricted to adults aged 18-64 (U.S. Department of Justice, 2017).

- Rate of violent victimization of females with disabilities (32.8 per thousand) was almost three times higher than the rate of victimization of females without a disability (11.4 per thousand).
- Rate of rape or sexual assault against persons with disabilities (2.1) was more than three times the rate of rape/sexual assault against persons without disabilities (0.6).
- A higher percentage of victims with disabilities were victimized by other relatives including parents and children (10.0%) compared to persons without disabilities (6.4%).
- Rate of victimization of males with disabilities (31.8 per thousand) was more than twice as high as the rate of victimization of males without a disability (14.1 per thousand).

The report also noted that while receipt of services was low, a higher percentage of victims with disabilities (12.3%) received assistance from a service agency than victims without disabilities (8.3%).

Mitra and Mouradian (2014), using data from the Behavioral Risk Factor Surveillance System (BRFSS) for 2005–2007, found that women with disabilities were more likely to report lifetime interpersonal violence, including physical abuse and sexual abuse, than women without disabilities. The BRFSS is a CDC coordinated random telephone health survey collecting self-reported information on the health status of adult men and women (ages 18-34, 34-54, and 55 plus) with and without disabilities. The study asked about interpersonal violence.

- Women with disabilities (35.5%) were more likely than all other groups to report all forms of lifetime interpersonal violence. Men with disabilities (19%) were more likely to report lifetime interpersonal violence than men without disabilities (13.3%).
- The proportions of any physical abuse were highest for women with disabilities (28.3%) followed by women without disabilities (16.6%), men with disabilities (13.7%) and men without disabilities (9.2%).
- Women with disabilities (17%) experienced lifetime sexual interpersonal violence compared to 8% of women without disabilities, 2.6% of men with disabilities and 1.1% of men without disabilities.
- Proportions of men with disabilities aged 35-54 (50.2%) had higher percentages of experiencing interpersonal violence than other age groups of men with disabilities.
- Women with disabilities aged 18-34 were the most likely to have experienced interpersonal violence (47.1%) compared to other age groups of women with disabilities.
- White non-Hispanic men had high rates of interpersonal violence (71.0%) approximately equal to white non-Hispanic women with disabilities (70.7%). Hispanic, Latino, and other races had much lower rates of interpersonal violence.

Grossman and Lundy (2008) studied sexual abuse and sexual assault of individuals with and without disabilities based on data from rape crisis centers in Illinois between 1998-2004. Of more than 60,000 children and adults, 2.5% were identified as having had one or more problems considered to be a disability including need for assistance with an activity of daily living, hearing



and visual impairments, using a wheel chair, immobility, a developmental disability, severe mental illness, or other chronic physical conditions. More than 60% of those with a disability (n=1093) had a developmental disability. More than half of the victims with a disability or special needs were adult survivors of incest or sexual abuse (21.1%) or adult sexual assault or abuse (47.6%). This compared to 25.1% of adults without a disability or special need being victims of incest or sexual abuse, and 39.4% being victims of adult sexual assault or abuse. Other findings were not broken out by age.

Lundy and Grossman (2009) conducted an analysis from the same database on 243,724 female adults who were 18-64 years (99%) and 65 years or older (1%). The final data set consisted of 2,495 women between 18-64 years and 2,470 women who were 65 years and older. Younger women were less likely to have a disability or special need (5.8%) than older women (15.6%).

While the authors did not compare the population with disabilities to the population without, they reported on several differences between the younger and older populations.

- Younger women were more likely to have some employment income than older women.
- Younger women were more likely to be single than older women.

Haydon, McRee, and Halpern (2011) studied unwanted sexual experiences of young adults (ages 26-32) with a physical disability. The authors analyzed the National Longitudinal Study of Adolescent Health (ADD Health), which is sponsored by the National Institutes of Child Health and Development and other federal agencies, and conducted by the Carolina Population Center at the University of North Carolina at Chapel Hill. The authors used several waves of data of a national representative sample of youth, and constructed a follow-up sample of 6,450 females and 5,428 males aged 24-27, 28-29, and 30-34. Less than 6% of the sample were young adults with a physical disability. Coerced sex was defined as being forced in a nonphysical way to have sexual activity against one's will; forced sex was defined as being physically forced to have sexual activity against one's will. Their findings included:

- No differences were found between women with or without a disability in terms of reporting coerced sexual experiences.
- No differences were found in coerced or forced sexual activity for women with below average or average scores on cognitive performance.
- Women with a physical disability had greater odds of reporting forced sexual experiences compared to those without a physical disability.
- Men with physical disabilities were twice as likely to experience coerced sex compared to men without disabilities.
- Socioeconomically disadvantaged women and men were more likely to report unwanted sexual experiences than those not disadvantaged.
- Childhood sexual abuse was consistently the strongest predictor of both forced and coerced sex for both men and women.

**Relevance for Practice and Research**

The articles discussed include only those who are abused in non-institutional settings. Self-reports of abuse by women with disabilities result in higher proportions of reports of abuse than are found in random samples. This is not a surprising finding, but is a recognition that cases known to APS and other agencies may be a serious undercount of the experiences of the population. Service agencies that know of abuse incidents may not be reporting to agencies which may further investigate the incident. Thus, further outreach to the community may be important.

Most of the identified research focused on intellectual disabilities and interpersonal violence including sexual assault and sexual abuse. There was little research on persons with physical limitations or chronic disabling diseases. Neglect, self-neglect, physical abuse, and emotional abuse were not studied as frequently. These gaps should be addressed in the future to provide additional information for practice.

While many studies have found that persons with disabilities have higher rates of abuse than those without, similarities among the two populations were also found. Further research that considers variations in living status and disability severity over the life cycle may be able to explain some of the differences in findings to date. Another factor that was not consistently researched was whether there were additional factors such as behavioral health issues or chronic illness. Such factors might influence the association of disability and abuse found in some studies but not in others.

Some research has indicated that women with disabilities experience abuse for longer periods of time than women without disabilities. In addition, it has been noted that childhood sexual abuse is a predictor for adult sexual abuse. This has ramifications for service agencies in that coordination may be needed between child protective services and adult protective services. APS may need to expand its outreach to the various groups of persons with one or more disabilities.

Hughes, Lund, and Gabrielli (2011) identified conflicting results may be the result of methodological differences, definitional differences, and differences in measures of prevalence. They recommended greater participation of persons with disabilities in research design and analysis. This recommendation has importance not only for researchers, but also practitioners and policy makers.

**IV. RISK FACTORS**

This section examines the literature on risk factors that may contribute to the vulnerability of an adult with a disability to becoming a potential victim of abuse. It includes articles about risk factors even if the authors or findings do not make an apparent direct connection to adults with disabilities.

Fisher, Baird, Currey, and Hodapp (2016, p. 115) use a definition of social vulnerability as occurring when “individuals are at risk of being unable to avoid adverse events that would affect their emotional, physical, or financial wellbeing.” While primarily focusing on events which if reported to APS would be accepted for investigation, we also consider literature that pertains to interpersonal violence, which may or may not come to the attention of APS.

A report by Disability Rights California (2003) classified the factors contributing to the problem of abuse and neglect of adults with developmental disabilities into the following categories:

- Victim factors
- Characteristics of assailants
- Disincentives for program administrators and staff
- Lack of training, experience, and socialized compliance
- Personal choice versus safety

In terms of victim factors, the report summarized the following factors (Disability Rights California 2003, p.3):

- Cognitive deficits which inhibit ability to protect oneself
- Dependence on others
- Communication impairments which impede ability to defend oneself or report
- Lack of training in sex education
- Lack of experience which encourages compliance rather than self-advocacy
- Fear of retribution

Nosek, Howland, and Young (1997) considered the following factors that may contribute to a risk of abuse. Specific types of disabilities were not discussed.

- Combined cultural devaluation of women compounded by age and disability
- Overprotection; lack of education and social experiences; and lack of support in developing capacity for self-protection
- Increased dependency and lack of economic independence

Strickler (2001) discussed levels of cognitive functioning as a factor contributing to likelihood of abuse. Marchetti and McCartney reported that persons with mild or moderate intellectual disability and high levels of adaptive behavior were more likely to have experienced abuse than those with high levels of retardation and low levels of adaptive behavior (as cited in Strickler, 2000). Murphy and Razza discussed that persons with mental retardation may fear being separated from their family and therefore are less likely to report abuse (as cited by Strickler, 2000).<sup>1</sup>

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<sup>1</sup> Marchetti, A.G. & McCartney, J. R. (1990). Abuse of persons with mental retardation: Characteristics of the abused, the abusers, and the informers. *Mental Retardation*, 28:367-371. Murphy, L. & Razza, N. Domestic violence against with women with mental retardation. In A. Roberts (Ed.), *Battered Women and Their Families* (2<sup>nd</sup> edition, pp. 271-290. New York: Springer), **quoted in** Strickler, H. (2001). Interaction between family violence and mental retardation. *Mental Retardation*, 39 (6): 461-471.

Fisher, Baird, Currey and Hodapp (2016) reviewed 23 articles in the international literature to summarize the history of vulnerability of adults with intellectual disabilities. They reported that the presence of an intellectual disability increases the risk of vulnerability. Additional factors include such characteristics as the following:

- Behavioral problems
- Poor personal competence
- Passive or avoidance decision making strategies
- Lack of friends.

In terms of sexual abuse, individuals with less sexual knowledge and less knowledge of abuse were more vulnerable. Those living in community settings were found to be at risk due to being unaware of risk or lacking the skills to respond in potential dangerous situations.

Much of the literature focuses on individuals with intellectual or cognitive disabilities. Researchers have also discussed the additional factors of education, employment, and support.

Siperstein, Heyman, and Stokes (2014) posited that among persons with an intellectual disability, employment may be an important protective factor to mediate the potential for neglect and emotional abuse. They used a national representative sample of 1,055 parents or guardians of adult children 21 years or older with an intellectual disability to discern the factors that lead to employment. The authors found that persons with a diagnosis of a behavioral or emotional problem in addition to an intellectual disability were almost two times less likely to be employed in either a sheltered setting or a competitive setting.

- Higher levels of adaptive behavior, such as practical skills involving skills of daily living, conceptual skills such as use of language and ability to tell time, and social skills including interpersonal skills and compliance, increased the odds of being employed in a competitive setting.
- Persons who were younger and were living independently had relatively higher odds of being employed in a competitive setting, while persons living in a group home had relatively higher odds of being employed in a sheltered setting.
- Most adults with and intellectual disability were not working at all and had either never worked (30%) or had previously worked and since left the work force (37%).

Fujiura (2010) used data from the 2007 ACS to determine the extent of financial support for adults with disabilities. His research question was, “To what extent will the demographics of aging influence the capacity of families to provide support to members with disabilities?” (p. 241). His analyses indicated that there were 27 million adults (aged 22 and older) with a disability living in a family household. Nearly one-third of these persons (32.3%) qualified as a dependent under IRS rules as compared to approximately 20% of adults without disabilities living in family households. Of those who were financially dependent, 13.3% were adult children of the primary income earner with a mean age of 35.5 years for the adult child and 62.7 years for the primary support person. While recognizing that family support cannot be measured solely in

monetary terms, the author argued that additional supports will be needed as the family support system ages. He concluded that there is “the potential for significant additional demands across multiple human service and income support programs” (Fujiura, 2010, p. 247).

Newman, Wanger, Cameto, Knokey, and Shaver (2010) used data from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS2) to examine changes in outcomes for young adults with disabilities after postsecondary school. Youth were between the ages of 18 and 21 years of age. On almost all measures they found improvements in quality of life among the 2005 cohort compared to the 1990 cohort. These included postsecondary enrollment rates, employment rates, and financial security. They also found differences by type of disability. However, they also noted that youth with disabilities in the 2005 cohort remained less likely than the general population to be enrolled in secondary education (46% compared to 63% in the general population).

Using the NLTS2, Morningstar, Trainor, and Murray (2015) examined outcomes for postsecondary school adults with learning disabilities, emotional disturbance, and ADHD. Outcomes, in general, were similar for these three types of disabilities. Overall, they expressed satisfaction with their life (60.7%) and being proud of themselves (81.0%). Over half responded they felt that their friends cared for them (52.4%), and felt safe (93.3%). More than half had engaged in high risk behaviors (64% had recent sexual intercourse, 80.9% were using contraceptives, 20.2% recently used drugs, and 13.9% had been in a fight within the last year).

Verbrugge, Latham, and Clarke (2017) analyzed data from the Health and Retirement Study (HRS) to examine aging with persistent disability. The HRS is an ongoing longitudinal panel survey of Americans aged 51 and older conducted by the Survey Research Center of the University of Michigan.. Persistent disability includes difficulties with physical tasks, including physical limitations (PLIM); household management, including instrumental activities of daily living (IADLs); and activities of personal care including activities of daily living (ADLs). They found that persistent disability is more common with the group of persons 65 years and older compared to those 51–64 years of age and that prevalence of persistent disability was higher for persons with PLIMs than for persons with low scores of IADLs or ADLs. They concluded that persistence of IADL/ADL disabilities results in increased dependency on caregivers which in turn increases vulnerability.

The Human Services Research Institute (2011) released a data brief on a convenience sample of 10,120 adults (18 years and older) living in 26 states either with a dual diagnosis of an intellectual disability and mental illness (35%, N=3,545) or solely with an intellectual disability (65%, N=6,575). The results were from the 2008-2009 National Core Indicators Consumer Survey Report. Persons with a dual diagnosis were less likely to live in a parent or relatives' home (15%) than persons without a dual diagnosis (38%). Those with a dual diagnosis were more likely to live in a group home (39%) than persons without a dual diagnosis (26%). They were more likely to report being lonely (49%) than persons without a dual diagnosis (39%).

There were no significant differences in the ability of the two groups to exercise choice in daily living and to being employed.

Wood, Hall, Hou, Wludyka, and Zhang (2007) examined access of quality health care for persons with intellectual or developmental disabilities (I/DD). They used the dataset of the State of Florida's Agency for Persons with Disabilities and studied the Medicaid records of 19,765 persons between the ages of 0 and 45, and older than 45 years. Their findings point to the complexity of knowing which factors contribute to risk, in this case risk of needing medical care in an emergency room.

- Not having a regular source of primary or specialty care resulted in higher use of emergency rooms for persons with I/DD similar to reports concerning persons without I/DD.
- Barriers to medical care, including a shortage of trained professionals and providers accepting Medicaid, were common.<sup>2</sup>

Degeneffe (2017) examined the future planning for adults with acquired brain injury (ABI) compared to those with intellectual disability. He discussed how the random onset of ABI results in major changes for family constellations, which are required to learn about new health and rehabilitative systems as well as prognoses for their family member. He argued that given insufficient support and financial assistance, negative indicators of caregiving stress were a potential result.

Based on a sample of 24 parents and adult siblings of a person with ABI, the author found that caregiving responsibilities were likely to be given to the adult sibling unless there were additional problems. If the disability was seen as a physical disability, the parents were more comfortable leaving care to adult siblings than if there were additional issues of emotional or behavioral stress. He suggested that the impact of the disability upon the individual and upon the family living situation could influence ability to care for the individual.

### **Relevance for Practice and Research**

The literature on risk factors of adults with disabilities did not identify which areas of vulnerability might result in abuse, but identified important aspects of disability that may be significant for assessing risk and for serving those who are abused.

- The research discussed variations among persons with disabilities and that types of risk factors may vary among the population and over the life span of the individual.
- Comparisons with the general population indicated differences in life circumstances related to economic independence and gainful employment, as well as education achievements.

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<sup>2</sup> See also U.S. Department of Health and Human Services. (2002). *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Rockville: MD.

- Not all individuals presented with the same set of risk factors, and over generalization of scope and type of risk factors is not supported by the research literature.
- There has been little research to indicate which areas of potential vulnerability relate to what types of maltreatment.
- Even large population studies that included many social factors related to the living conditions, emotional status, educational, and employment status of persons with disabilities, did not include questions about maltreatment.
- Policy makers could explore if additional questions on abuse could be included in ongoing national studies such as the National Longitudinal Transition Study, the Health and Retirement Study, and the American Community Study. Such questions might also be added to the National Core Indicators Consumer Survey Report.

## V. SERVICE RESPONSES

Many researchers have discussed what the findings about the abuse of persons with disabilities indicates in terms of improving services for victims and those at risk of being a victim.

Nosek, Howland, and Young (1997) discussed several policy implications in terms of services for women with disabilities who had been abused.

- Service programs may have barriers of lack of access due to architectural barriers and accessibility barriers in terms of hours of operation and appropriate programs.
- Service programs are reluctant to report or refer victims of abuse.
- Service programs may lack understanding of women's issues including sexuality of women with disabilities.
- Persons may have insufficient access to personal assistants.
- Most law enforcement personnel have little training in needs of persons with disabilities.
- Many APS personnel are overwhelmed and under trained.
- Persons lack accessibility to affordable legal services.
- Community services are not well integrated.

Nosek et al (1997), and Mitchell and Buchele-Ash (2000) made recommendations for improvements. They included the following:

- Modify shelters for battered women to improve accessibility.
- Improve training of mandated reporters.
- Increase education of individuals with disabilities regarding their rights and self-protection.
- Train law enforcement personnel, prosecutors, and judges on ability of victims to be witnesses. Adoption of the presumed competence rule.
- Fund services adequately.
- Improve advocacy communication strategies.
- Increase data on disability status in case management information systems.

Strickler (2001) discussed the following implications for practice:

- Practitioners must know more about the victim than just the intellectual abilities. Rather, the individual's abilities and living status are important to understand.
- Comprehensive assessments are necessary, as well evaluation of skills.
- Individual treatment plans, which may include therapeutic interventions, are necessary.
- Practitioners must be trained in family violence, sexuality, and intellectual disabilities.
- Practitioners must also consult with counselors or psychiatrists if there are psychiatric issues.

Lund (2011) conducted a literature review of community-based services of adults with disabilities who experienced interpersonal violence. Some of her findings that were not mentioned in other recommendations include:

- Behavioral and cognitive interventions may be useful, as well as longer term services.
- Attention to the needs of the Deaf and Hard of Hearing who may not identify as having a disability is important.

Lund also suggested the need for additional research on areas of direct importance for future improvements of interventions.

- Expansion of research on abuse prevention
- Randomized control trials of interventions and treatment protocols
- Attention to disability-related abuse such as denying transportation to a person with ambulatory needs
- Increased attention to abuse of men with disabilities and programs that serve men
- Development and analysis of interventions that require relatively low level of verbal interaction
- Increased attention to the intersection of disability status and racial and ethnicity identity in conjunction with types of maltreatment

Focht-New, Barol, Clements, and Milliken (2008) emphasized that interventions serving adults with disabilities who have experienced interpersonal violence cannot be short term, but rather, victims need longer term supportive environments and often therapeutic interventions. They recommended that these interventions be adjusted for levels of communication and understanding. They also emphasized that caregivers must be supported.

Faccini and Saide (2011) reported on a lack of standardized methods of interviewing and analyzing accounts of physical, emotional, and sexual abuse from persons with an intellectual disability. They surveyed 31 psychologists who had a caseload of persons with disabilities. More than half reported that they did not know how to analyze the results of their interviews.

Burke and Heller (2016) reported on the disparities in unmet service needs of adults with disabilities based on a survey of 234 familial caregivers. While these adults were not necessarily victims of abuse, types of unmet needs are a useful framework for understanding potential service options.



- More than a third of caregivers reported a need for training about service planning (52.14%), recreational services (44.02%), transportation services (41.88%), community employment (40.60%), networking with other families (40.60%), training or information about adult services (37.61%).
- Some additional service needs included assistive technology or home modifications (32.05%), day programs or sheltered workshop (31.62%), and respite (3.20%).

The need for collaboration among multiple agencies was discussed in several articles. One of the major topics was the need for additional collaboration between protective services and victim services.

Brandl (2000) wrote about the need to understand that victims of abuse are not dependent upon their abusers for care but rather the abusers are dependent upon the victims for financial and emotional support. She posited that rather than a paradigm of caregiver stress, the paradigm of power and control as recognized in domestic abuse needs to be applied in many situations of elder abuse. The relevant corollaries to assessing persons with disabilities were not discussed in this article, but several factors – such as isolation of the client or victim; the need to empower the victim by empathetic listening and offering options; the importance of working with experts; and the ability of service providers to initiate safety planning and refer clients to appropriate service agencies – are all relevant for persons with disabilities.

Otto and Quinn (2007) examined barriers to collaboration between APS and domestic violence programs. They summarized the following barriers between the two service systems and noted some promising practices in various localities:

- Differences in terms and definitions including terms such as victims, survivors, mistreatment, intimate, and abuse
- Lack of familiarity by both systems with the population and with non-English speaking victims
- Underserving male victims by the domestic violence system
- Tensions about mandating reporting and the use of involuntary services among the domestic violence services provider community
- Unsuitable housing accommodation options
- Health issues may be challenging for both service systems, especially of adults with disabilities
- Lack of funding for cross-training

Cramer and Brady (2013) reviewed issues faced by APS in serving persons with disabilities based on their experience in the Commonwealth of Virginia. They described that APS seeks to protect vulnerable adults, while DV advocates “tend to view persons with disabilities and older adults as capable of making their own decisions, except under rare and unique circumstances” (Cramer and Brady, 2013, p. 461). The authors suggested three areas of improved collaboration between the two service systems:

- Increase knowledge by each service sector of the other system through cross-training and development of multi-disciplinary teams
- Emphasize common ground rather than differences
- Practicing collaborating on areas of mutual interests and needs

Jackson (2017) published a comprehensive summary of the literature comparing APS and victim services. Her review indicated that there are many areas of similarity between the two fields and four main areas of difference. These four areas were identified as areas in which DV may find APS as intrusive to beneficial services to their clients.

- State statutes often require mandatory reporting by DV providers.
- Domestic workers believe that investigations by APS may result in greater danger to their clients.
- APS is obligated to screen for capacity if they suspect diminished cognitive capacity.
- APS may impose involuntary services.

Jackson suggested several areas for future research. While not specifically discussing victims with disabilities, evaluation research on these topics that identify persons with disabilities would fill an important gap in knowledge.

- Interventions which separate victims from perpetrators
- Services to perpetrators as a means of insuring future safety of the victims
- Ways to engage victims with disabilities in services
- Assessment of mandatory versus voluntary reporting
- Outcomes of short term and longer-term services

Mixson (2010) observed that program policy in Texas has narrowed the definition of substantial disability and this has resulted in fewer routine filings for disability and Supplemental Security Income.

Barriera, Espey, Fishbein, Moran, and Flannery (2000) reported on the need to collaborate between mental illness service systems and substance abuse treatment systems. They discussed an initiative that developed a quality improvement collaborative (QIC) which included a leadership council among state agencies. These councils were also replicated at the regional level. Such a model could be expanded to include service sectors for APS and those that specialize in serving persons with disabilities.

Nosek et al. (2001) argued for all systems, including medical and other health providers, which come into contact with women with disabilities to assist them in finding community resources to help them avoid or remove abuse in their lives.

McDonald, Conroy, Kim, LoBraico, Prather, and Olick (2016) found divergences in perceptions of how to safeguard the rights of participants in disability research. They suggested that an understanding of issues related to recruitment, communication of objectives of the research,

consent procedures, involvement of caregivers, and privacy and confidentiality will be critical for furthering research and for improving service options.

### **Relevance for Practice and Research**

The literature on the service response to abuse and neglect of persons with disabilities has largely focused on needs for improvement. We identified no research that conducted evaluations of different service interventions or of different outcomes for this population served by APS. The literature, however, did have common themes for areas for improvement. These included increased collaboration among service providers, increased cross training for those involved in resolving situations of abuse and neglect, and increased research on interventions used to serve persons who have been abused.

The literature gives some glimpses of areas that could be considered as program improvements.

- Consideration of the role of long term services for persons with disabilities who have been abused
- Coordination with child protective services to understand early childhood abuse of adult victims
- Further examination of the use of involuntary services
- Not only greater collaboration with agencies that address domestic violence but also with other health prevention and promotion efforts
- Involvement of persons with disabilities in the design of programs and research efforts while safeguarding their privacy
- Increased sharing of concepts of abuse and neglect of adults with agencies serving persons with disabilities as well as potential victims themselves

## **VI. SUMMARY**

The literature on persons with disabilities who have been maltreated is widely dispersed in journals with a focus on disability, rehabilitation, and interpersonal violence. Some major national surveys have included research questions on disability, but relatively few included questions on maltreatment other than interpersonal violence. Smaller studies also focused on interpersonal violence. The distinction between interpersonal violence (including intimate partner violence) that would become the responsibility of APS and that which would not become the responsibility of APS was not always clear in the research. Furthermore, research about the neglect, self-neglect, financial exploitation, and emotional maltreatment of adults with disabilities was scarce. Some studies discussed all adults, including older adults, or include children and adults in their analyses, which further complicates a more refined understanding of the problem.

The literature clearly demonstrates that persons with disabilities are the subject of abuse. The extent of abuse over the lifespan may not be visible to service providers who see clients during a specific time of life. Continuity of contact and continuity of care are not common among

providers of service to persons with disabilities. The literature indicates that persons with disabilities may benefit from the option for long term involvement with support systems across a range of domains, including social services, education, and employment, without being mandatory or intrusive, except in specific circumstances of last resort. Specific awareness training of how to protect oneself against abuse and how to respond to abuse was suggested for persons with intellectual disabilities.

The literature is not clear on which personal vulnerabilities pose the most risk of abuse, independent of characteristics of perpetrators of abuse and neglect. Further research that examines both the characteristics of abusers and the characteristics of victims may assist in greater understanding of necessary and appropriate services and interventions.

The literature is also unclear on whether persons with certain types of disabilities at certain points during the life cycle are more vulnerable to potential abuse. Very little research exists on other forms of disability besides intellectual disabilities. The literature suggests that issues of mental or behavioral health further complicate understanding vulnerability and exposure to abuse.

Two studies included the use of administrative data sets of service provider agencies. This area of data collection and analysis poses great potential as the field of data analysis develops new techniques for understanding even relatively rare events, such as may be seen by local APS agencies and their staffs.

Given the growth in literature on this topic in the past decade, coming decades could result in increased knowledge about this understudied and underserved population. More consistent measurement and definitions, as well as more precise identification of types of disabilities and types of maltreatment, will be needed to achieve the goal of utility and relevance for practitioners, researchers, and policy makers.

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