

Abuse and Neglect of Adults with Developmental Disabilities:

A Public Health Priority for the State of California

Note: When this report was originally published, we were known as Protection & Advocacy, Inc. (PAI). In October 2008, we changed our name from PAI to Disability Rights California.

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Forward

This report is the product of a collaboration of the four agencies in California authorized under the Developmental Disabilities Assistance and Bill of Rights Act (2000) (DD Act). 42 U.S.C. §§ 15001 et seq.

- 1. Protection and Advocacy, Inc.
- 2. State Council on Developmental Disabilities

3. California's University Centers for Excellence in Developmental Disabilities Education, Research and Service:

- University of Southern California University Affiliated Program, and
- the Tarjan Center for Developmental Disabilities at the University of California Los Angeles

While each agency has a specific mandate and designated activities under the DD Act, they are jointly responsible for quality assurance activities, which involve (1) monitoring; (2) training; and (3) and other activities to assure the appropriate coordination and integration of services, to ensure that individuals with developmental disabilities will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights, and will not be subject to the inappropriate use of restraints or seclusion. See 42 U.S.C. § 15002(23). This joint responsibility is the catalyst for this report.

Many individuals with disabilities are victims of abuse, neglect, and criminal activity. Due to the breadth and complexity of issues underlying this topic, we have deliberately narrowed the focus of this report to:

1. Individuals with developmental disabilities as defined by California's Lanterman Act¹;

2. Victims of physical abuse, sexual abuse, and/or violence²;

¹ Under state law, a developmental disability refers to a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual; includes mental retardation, cerebral palsy, epilepsy and autism, or disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation. Welf. & Inst. Code § 4512(a).

 $^{^{2}}$ This report does not encompass regulatory and policy issues particular to (a) financial abuse, (b) illegal use of medication to restrain and control individuals, and (c) child abuse.

3. Adults (individuals with developmental disabilities over the age of 18), not children.

The content of this report and its recommendations were derived from literature review, analyses of existing statutes and regulations for a variety of systems, and interviews with knowledgeable individuals within the existing systems. Experts interviewed were from the developmental disability, advocacy, and criminal justice systems. They included staff of the Department of Developmental Services (Information Services and Residential Services), regional centers, Organization of Area Boards, Office of Clients Rights Advocacy, Department of Mental Health Crime Victims with Disabilities Initiative (California Health and Human Services Agency), Crime Victims with Disabilities pilot programs (at Easter Seals Superior County, Ventura County District Attorney's Office, and the USC UAP), the Arc California, State Long-Term Care Ombudsman's office, Adult Protective Services, Child Protective Services, law enforcement, and Los Angeles County Mental Health Court 95.

A preliminary draft was distributed to representatives of developmental services and the criminal justice system, specifically: Department of Developmental Services Office of Human Rights and Advocacy Services; Department of Mental Health Crime Victims with Disabilities Initiative; Child and Youth Services, Governor's Office Criminal Justice Planning; the Association of Regional Center Agencies; and the Organization of Area Boards. All members of the State Council on Developmental Disabilities were invited to submit written comments to the final draft. Written comments were submitted by the California Association of State Hospital Parent Councils for the Retarded (CASH-PCR), the Department of Aging, the Department of Developmental Services, and the Department of Social Services. The authors considered each written comment and included all content that contributed to the factual accuracy of the report and was relevant to the general subject matter.

The audience for this report is the California Legislature and other public policymakers, as we believe this report raises such broad issues of systems inadequacy that remedies must be of a broad and sweeping nature. We expect that this report will also be of interest to individuals with disabilities, family members, state agency executive and administrative staff, executive and front-line staff of regional centers and their provider network, executive and front-line staff of law enforcement and the criminal justice system (including prosecutors, judges, and victim/witness assistance programs), and mental health and other related professionals mandated to serve Californians with developmental disabilities.

It should be noted that this report's recommendations present remedies for problems identified. Our recommendations were not influenced by potential cost; instead, we proposed a set of changes likely to eliminate the barriers identified in this report. Our intent is to urge the development of a system which protects Californians with developmental disabilities from abuse and neglect and holds their abusers accountable for their action. While it would be imprudent to ignore cost when systems are established, policymakers are best positioned to consider these issues when making decisions that affect the lives of California citizens with developmental disabilities.

Pseudonyms have been used throughout this report for all the names of individuals described in the case examples.

This report describes the nature and extent of abuse and neglect perpetrated against people with developmental disabilities and identifies systemic issues that underlie the increased risk for victimization of this population. Three major findings are presented and discussed.

- 1. Abuse and neglect of people with developmental disabilities is a public health problem because Californians with developmental disabilities are likely to be:
 - victimized at a much higher rate (4-10 times more frequently) than other citizens;
 - at higher risk for re-victimization;
 - frequently severely abused and for longer periods of time;
 - most frequently victimized in their residences by persons they know and who may be responsible for their services and supports; and
 - inadequately educated and supported to recognize, resist, and seek alternatives to abusive situations.
- 2. The current system of protections is inadequate for victims with developmental disabilities because it:
 - results in the underreporting of abuse, neglect, and victimization in this population;
 - fails to collect reliable, valid data concerning the scope of the problem;
 - is complex and confusing to victims and mandated reporters; and
 - is generally unsuccessful in prosecuting perpetrators.

3. Many individuals within the abuse response and criminal justice systems lack training and expertise working with people with developmental disabilities.

These findings create an obligation for the Legislature to address significant reform. Eight recommendations are made:

1. Eliminating abuse and neglect of people with developmental disabilities must be made a public health priority in California.

- 2. The Legislature must designate a lead agency with authority and responsibility to coordinate system reform.
- **3.** An integrated data collection must be implemented to document the incidence of abuse and neglect and track the outcomes of criminal investigations and prosecutions.
- 4. Regional centers must have an increased and uniform role in coordinating the response and services provided victims.
- 5. Incidents of abuse and neglect in long-term care facilities must be investigated by law enforcement or Adult Protective Services, not the long-term care Ombudsman.
- 6. Victims with developmental disabilities must be provided new protections from perpetrators.
- 7. The Department of Developmental Services must continue to implement the Department of Justice recommendations regarding the law enforcement division of developmental centers.
- 8. All agencies involved in the abuse response system must receive mandatory training regarding working with individuals with developmental disabilities.

Chapter 1:The Nature and Extent of Physical and Sexual AbuseInvolving Individuals with Developmental Disabilities

A. Frequency and Severity of the Problem

Although violent crime has declined in the United States over the past several years, people with developmental disabilities remain at disproportionately high risk for violent victimization, abuse and neglect (Petersilia et al., 2001). While the scientific evidence continues to be limited, international studies from Canada, Australia, Great Britain, and the United States have documented high rates of violence and abuse affecting people with disabilities (Ibid.). Experts conservatively estimate that people with disabilities are at least four times more likely to be victimized than people without disabilities (Sobsey, 1994; Toronto Star, 1990). Individuals with an intellectual impairment are at the highest risk of victimization (c.f., Sobsey & Doe, 1991).

Some studies estimate that close to 80% of women with developmental disabilities have been sexually assaulted at some point in their lives (Sorensen, 2002; Lumley and Miltenberger, 1997). Other studies have found the rate for sexual assault was anywhere between 2-10 times higher for people with disabilities when compared to people without disabilities (Wilson & Brewer, 1992; Baladerian, 1991; Muccigrosso, 1991; Westat Inc, 1993).

Similar findings have been documented from studies of Californians with disabilities. Hard (1986) found that, of 95 adult Californians with developmental disabilities surveyed, 83% of the women and 32% of the men had been sexually assaulted. A later study of San Francisco Bay area residents with mild mental retardation found that nearly 80% of the women and 54% of the men had been sexually abused at least once (Stromsness, 1993). While many feel that living in the community carries inherent risks, it is notable that some studies have found that crime rates are higher for victims with disabilities in institutions, group homes and other segregated facilities (Sobsey & Mansell, 1990; Roeher Inst., 1994).

Adding to these alarming incidence rates, studies show that people with disabilities are more likely to experience more severe abuse, experience abuse for a longer duration, be victims of multiple episodes, and be victims of a larger number of perpetrators (Schaller & Fieberg, 1998; Sobsey & Doe, 1991; Young et al., 1997).

The authors are aware that some of the above data must be interpreted cautiously. Accurate estimates regarding the incidence of abuse or neglect of persons with developmental disabilities specifically are difficult to obtain. Consequently, someresearch referenced in this report comes from studies of individuals with a broad range of disabilities. Much of the research on victimization of people with disabilities does not delineate specific sub-populations. Public records of violence against individuals usually do not indicate whether or not the victim has a disability, let alone a developmental disability (Curry et al., 2001). Reliable studies focusing specifically on Californians with developmental disabilities who have been victims of physical or sexual abuse are small in number. Furthermore, there is no coordinated system to collect data on and track outcomes of victims with disabilities from the initial allegation, to the initial report, to prosecution and finally to conviction. However, most experts agree that research findings involving other groups of people with disabilities.

B. Underreporting and Lower Rates of Prosecution and Conviction

Contributing to the gravity of this problem, most crimes against people with developmental disabilities tend to go unreported (Sorensen, 2002). Wilson & Brewer (1992) found that 71% of crimes against people with severe mental retardation go unreported. Again disputing beliefs about the safety of congregate settings, Powers, Mooney, & Nunno (1990) suggested that 80-85% of criminal abuse of residents in institutions never reach the proper authorities.

Research findings document excessively low rates of prosecution and conviction of crimes against people with disabilities. One study found that 65% of sexual assault cases reported to police were not prosecuted when the victim had a disability (Sobsey & Varnhaggen, 1991). A more recent survey in Boston found that only 5% of serious crimes against people with disabilities were prosecuted compared to 70% for similar crimes against people without disabilities (Boston Globe, 2001). A study of sexual assaults of people with intellectual disabilities in Britain found that police investigated only 21% of cases reported and only 9 % were referred by police for prosecution. Just two cases (less that 1%) proceeded to court with only one resulting in conviction. (Brown & Stein, 1997).

C. Factors Contributing to the Problem

1. Victim Factors

A number of studies suggest that people with disabilities have different profiles for victimization and abuse than the non-disabled population (c.f., Petersilia et al., 2001; Sobsey & Varnhagen, 1991). These include: (1) cognitive deficits which may make it difficult for the victim to recognize unlawful activity and/or their rights to safety and protection; (2) dependence on others to assist with activities of daily living and personal care; (3) presence of communication or physical impairments which limit their ability to verbally or physically defend against a perpetrator and disclose abuse (Sobsey & Varnhagen, 1991); (4) lack of training in sex education; (5) lack of experience and socialization which encourages compliance rather than self-advocacy (Lumley & Miltenberger, 1997; Sobsey, 1994; Tharinger et al., 1990); and (6) fear of retribution from the perpetrator if they do report or fear that they will have to move from their home as a solution to the abuse incident.

Some persons with developmental disabilities must rely on others to recognize that they are being abused and to take appropriate action to notify investigators from responsible agencies. Yet few family members, friends, and providers are adequately trained to recognize signs of abuse in individuals with developmental disabilities and to assist victims to access the criminal justice and/or social service system.

Even if they want to report or stop the abuse, some individuals may not be able to formulate and execute a plan of response, some may not be able to physically escape from an abusive environment, and some may not be able to travel to a police station to file a report. In addition, for those individuals who want to report, the presence of an array of communication difficulties frequently leads to frustration when officers taking the report cannot understand the victim.

Vulnerable Man Repeatedly Abused

Vic Palmer was an 18-year-old man with Down's Syndrome. He was non-verbal but understood his native language and English. Vic was able to communicate using gestures, signs, and pointing to pictures. In March 2000, Vic arrived at school from his group home with a black eye. No inquiries were made or abuse reports filed. A week later, Vic appeared at school with bruises on his chin (concealed with make-up) and scratches on his back and chest. The school reported the injuries to Adult Protective Services (APS) and the regional center, but returned Vic to his group home. A week passed before APS investigated. They did not attempt to interview Vic or ask the regional center to assist with the interview. APS concluded that the abuse could not be substantiated. The regional center did not receive APS's report until three months after Vic's death.

Over a month later, Vic's father contacted the regional center about new bruises on Vic's face and to express concern about how staff at the group home were treating his son. Vic remained at the group home. Four days later he was rushed to the local hospital where he died. According to the coroner, Vic had been severely beaten, sustaining multiple traumatic injuries to the base of his skull and to his abdomen, including traumatic lacerations of his liver. Investigators suspect that the perpetrator was a staff member at the group home, but the investigation has been closed without any arrests.

2. Assailants

Regardless of the type of disability or whether the abuse is emotional, physical, or sexual, people who provide care and support to individuals with disabilities are often the same people who victimize them – people the victims know and trust (Petersilia et al., 2001; Nosek et al, 1997; Marchetti & McCartney, 1990). It is estimated that risk of abuse increases by 78% due to the vulnerability of people with developmental disabilities and their need for personal assistance services (c.f., Sobsey and Doe, 1991; Young et al., 1997; Curry & Powers, 1999). In a survey of individuals with disabilities who had been abused, 96% of the cases involved perpetrators who were known to their victim (Sobsey and Doe, 1991). The largest group of offenders (44%) were individuals who had a relationship with the victim specifically because of their disability (27.7% disability service providers, 5.4% specialized transportation, 4.3% specialized foster parents and 6.5% other disabled individuals). Mansell et al. (1992) similarly found that 26% of perpetrators were

paid care givers providing services related to the victim's disability and 11% were other service providers.

Homes and other residences are the most common setting for abuse (Sobsey, 1994; Furey, 1994; Turk & Brown, 1992). One study found that 58% of the offenses took place in the homes of either the victim (48%) or the perpetrator (10%) (Turk and Brown, 1992). As individuals with developmental disabilities have access to a wider array of living arrangements³, states must ensure that systems are in place to prevent abuse not only in congregate facilities, but also in the community.

Sexual Encounter with Care Giver

Lisa Russell was a 47-year-old woman with cerebral palsy and mild mental retardation living in a large residential facility. Miguel Chase, a certified nurse assistant (CNA) at the facility enticed Ms. Russell to a remote area of the campus and had a sexual encounter with her. Although she went with Chase willingly, Ms. Russell later said she had anticipated the rendezvous would involve "making out" but not sexual intercourse.

The following morning Ms. Russell reported the encounter and administrators quickly interviewed her. She was not provided with an advocate or other support during the interview. They asked leading and compound questions, including questions that led Ms. Russell to state that the encounter was consensual. The answers to these questions were later relied upon by law enforcement investigators. The facility did not report the sexual encounter as dependent adult abuse.

Chase was fired, lost his CNA certificate, but was never prosecuted. As a result of that sexual encounter, Ms. Russell was infected with cytomegalovirus and died less than six weeks later.

3. Disincentives for Program Administrators and Staff

The current system inadvertently creates disincentives for program administrators and staff to report incidents involving individuals with developmental disabilities. Non-abusing staff of care facilities may fear reprisals or retribution from their administrators or their peers (The Edmonton Journal, 1990; Sorenson, 2002).

³ With a national movement supporting personal choice, many individuals with developmental disabilities are choosing to live in small community settings. Between 1982 and 1997, the number of persons with mental retardation or developmental disabilities living in settings of 3 or fewer persons rose 427%. Nationally, the average daily population of large state MR/DD facilities decreased by 56.1% from 1980 to 1997. (Prouty and Lakin, 1998).

Administrators may fear negative publicity, questions about their competence, damage to their careers, or loss of licenses for their facilities (Sorenson, 2002). Experts have reported that the negative consequences of publicity about a crime or abuse in a facility can be severe to that institution. Consequently, facilities and/or their managers may ignore or minimize abuse or neglect allegations.

4. Lack of Training, Experience, and Socialized Compliance

Other authors have noted that individuals with disabilities may have a specific vulnerability to abuse due to compliance training and a desire to "fit in" and be liked (Sobsey, 1994; Tharinger et al., 1990). These vulnerabilities are highlighted in a study by Conte, Wolfe, and Smith (1989), who interviewed a group of child abuse perpetrators who had successfully completed treatment. They found that perpetrators seek out children who are friendly, compliant and unlikely to disclose abuse. Compliance training has been implicated in abuse cases with adults, when care givers are the perpetrators (Tharinger et al., 1990). Such compliance is further reinforced by a dependence on care givers and the relatively powerless relationship which exists between individuals with disabilities and their service providers. People with mental retardation and other cognitive or intellectual impairments may not realize that they can refuse unwanted sexual contact (Reynolds, n.d.). Lumley & Miltenberger (1997) suggest that because persons with mental retardation often do not receive formal sex education, they may have limited knowledge and ability to fully consent to sexual activity and to protect themselves from potentially abusive situations. Some individuals in today's society believe individuals with disabilities are asexual and thus do not need sexual education (Sobsey, 1994). To the contrary, it has been found that individuals with disabilities typically exhibit normal sexual development and desires (Tharinger, et al., 1990). When sex education is not provided, an individual with a disability will be less likely to identify and/or respond assertively to inappropriate touching or behaviors, thereby contributing to the perception by others that this may be consensual sexual activity (Lumley & Miltenberger, 1997; Tharinger et al., 1990).

D. Personal Choice Versus Safety

When discussing the broad arena of abuse and neglect involving people with disabilities, a dynamic tension between personal choice and personal safety surfaces. Simply stated, this tension refers to the inherent conflict between the dignity of risk associated with increased self-direction and the competing inclination to provide protections for vulnerable individuals, which can negate personal choice and self-determination. While an appropriate discussion of this

tension is not possible in this report, federal and state law are clear that the appropriate response of society and systems responsible for protecting citizens with disabilities must not unduly suppress choice and self-direction. 42 U.S.C. 15002(23); Welf. & Inst. Code §§ 4646.7 (a)(1) & 4646.5(a)(2).

Chapter 2: Current System of Protections for Victims of Abuse and Neglect with Developmental Disabilities

California's system for responding to allegations of abuse and neglect involving people with developmental disabilities is governed by multiple sets of statutes and regulations. See Table 1. Each addresses a different component, from the initial response and investigation, to safeguarding the victim, to the tertiary action by licensing entities of facilities and/or individual perpetrators. For a licensed care facility, this means the same abuse or neglect allegation must be reported to several different entities. While this system attempts to provide for comprehensive protections for vulnerable populations, it is cumbersome and confusing to victims and reporters of abuse or neglect. What constitutes a reportable event varies. Reporters who meet their obligations under one statute may not meet their obligations under another statute. A report to one entity under one mandate does not automatically prompt a report to another entity under a different mandate. This leads to incomplete reporting and, ultimately, inadequate investigation and response.

A. Elder Abuse and Dependent Adult Civil Protection Act

The Elder Abuse and Dependent Adult Civil Protection Act (the Abuse Reporting Act) is the most victim and consumer-focused of the various abuse and neglect laws and regulations. California enacted the Abuse Reporting Act to protect vulnerable persons⁴ by requiring individuals providing care and services for elders and dependent adults in health facilities and in the community to report instances of abuse and neglect. Welf. & Inst. Code §§ 15600 et seq. Although abuse allegations may be reported by anyone having knowledge of the incident, the Abuse Reporting Act requires certain individuals (mandated reporters) to report known or suspected abuse or neglect of dependent adults and elders. Any person who has responsibility for the care or custody of a dependent adult is a mandated reporter. They are required to report incidents that reasonably appear to be abuse or neglect of dependent adults and elders, whether directly observed by, reported to, or based upon knowledge of the reporter. Reportable incidents include physical abuse, abandonment, isolation, financial abuse, and neglect. Welf. & Inst. Code §

⁴ Vulnerable persons include: elderly (any person 65 years of age or older) and dependent adults (any person, between the ages of 18 and 64 years, who has physical or mental limitations that restrict his or her ability to carry out normal activities or to protect his or her rights, including but not limited to, persons who have physical or developmental disabilities or whose physical or mental abilities have diminished with age). Welf. & Inst. Code §§ 15610.23 and 15610.27.

15630(b)(1). Mandated reporters have no duty to conduct an investigation before making the required report. Welf. & Inst. Code § 15630(b)(2)(B). The Abuse Reporting Act also designates specific penalties for mandated reporters who fail to report. Welf. & Inst. Code § 15630(h).

Mandated reporters must notify specific agencies which conduct an investigation. If abuse occurs in a long-term care facility⁵, the report must be made to either the local long-term care Ombudsman (Ombudsman) or local law enforcement agency. If the abuse occurs in a state developmental center, the report must be made to the Department of Developmental Services (DDS) investigators or to the local law enforcement agency. Abuse occurring anywhere else is reported to Adult Protective Services (APS) or local law enforcement. Welf. & Inst. Code §15630(b).

The following are descriptions of the initial investigative entities notified by mandated reporters. While these primary investigators have the general goal of protecting the dependent adult from abuse, they approach allegations of abuse from different perspectives, pursuant to their agency's mandate. No direction is offered to a mandated reporter about how to select which entity is notified. However, the determination about who is notified has significant ramifications as to the quality and timeliness of the investigation.

⁵ These do not include state developmental centers.

	Pursuant to the Abuse Reporting Act				Pursuant to California Regulations		
	Law Enforcement	Investigations in Dev. Ctrs.	APS	Long-Term Care Ombudsman	Regional Center	Community Care Licensing	DHS Licensing & Certification
Oversight	Local Police or Sheriff's Department	Dept. of Developmental Services	Dept. of Social Services	Dept. of Aging	Dept. of Developmental Services	Dept. of Social Services	Dept. of Health Services
Statutory Authority	WIC §§15600 et seq.	WIC §§15600 et seq.	WIC §§15600 et seq.	WIC §§9700, et seq.; 42 U.S.C. § 3058(i)	Cal. Code of Regs. tit. 17	Cal. Code of Regs. tit. 22	Cal. Code of Regs. tit. 22
Targeted Population: Age	All ages	All ages	65 years or older; dependent adults age 18-64	60 or older	All ages	All ages	All ages
Disability	All persons	Residents of developmental centers	Elderly; Individuals with mental or physical impairments that restrict ability to complete ADLs	Elderly; Dependent adults	Developmental disabilities: autism, epilepsy, cerebral palsy, MR, conditions closely related to MR	Residents of community or non- medical facilities	Residents of healthcare facilities
Location	Anywhere	Developmental Center	Community Setting	Long-term Care Facility	Anywhere	Licensed Community Facility	Licensed Healthcare Facilities

Table 1: Agencies receiving and investigating reports of abuse or neglect involving adults with disabilities.

1. Local Law Enforcement

No matter where an incident takes place, the local municipal police department and/or county sheriff's department may respond. Yet, many reports never reach law enforcement even though the incident may involve a crime.⁶ Law enforcement agencies investigate crimes and present the evidence from those investigations to the District Attorney's office. An investigation by law enforcement is crucial to prosecuting predators. The District Attorney's office decides whether to file charges for prosecution.

Law enforcement is often not the first investigator to respond to incidents of abuse or neglect in facilities. By law, if it is likely a crime has been committed, law enforcement must be contacted to investigate. However, law enforcement reports receiving relatively few abuse or neglect allegations involving victims with developmental disabilities (in contrast to the number of reports involving elderly victims), and the vast majority of these are reported by staff of small communitybased facilities where consumers live. Self-reports by consumers living in the community are rare.

2. Investigations in Developmental Centers

Incidents of suspected abuse or neglect at developmental centers are documented by facility staff and reported to law enforcement personnel employed by DDS⁷ (stationed at the developmental centers) for investigation. Developmental center law enforcement investigates both administrative (i.e. employment or personnel) and criminal matters. Akin to community law enforcement, developmental center law enforcement personnel are the primary investigators of criminal activity and evidence collected may be forwarded directly to the District's Attorney's office for consideration of prosecution. Because the process of notifying developmental center law enforcement personnel of an incident varies from one developmental center to another, the quality and timeliness of investigations also varies. DDS

⁶ Crimes upon a dependent adult include infliction of bodily harm, death, physical pain and/or mental suffering of any dependent adult; placing a dependent adult in a situation in which his/her person or health is endangered; theft or embezzlement with respect to property of a dependent adult; and false imprisonment of the dependent adult. Penal Code § 368.

⁷ The law enforcement division of each developmental center employs hospital peace officers and special investigators to keep the peace, prevent crime, investigate offenses on developmental center property, and protect residents, employees, visitors, and facility property. DDS requires that law enforcement services be available 24 hours a day in each developmental center.

does not consistently notify local law enforcement agencies of abuse. Local law enforcement rarely takes the lead on investigations at developmental centers.

In May of 2000, Senator Wesley Chesbro, Chair of the California Senate Select Committee on Developmental Disabilities and Mental Health, requested that Bill Lockyer, Attorney General State of California, authorize an investigation by the Department of Justice (DOJ) into the quality of police and investigative activities at the state developmental centers. That investigation was completed and a report with findings and recommendations was issued in March 2002. In August of 2001, in response to chaptered legislation⁸, developmental centers began implementing new procedures in abuse reporting. The procedures include reporting all resident deaths and serious injuries of unknown origin to the local law enforcement agency in the community and providing annual written training materials to all employees regarding mandatory reporting requirements.

3. Adult Protective Services (APS)

APS constitutes the essential safety net for vulnerable adult populations living in the community, including the prompt investigation of all situations involving elders (age 65 or older) and dependent adults (18-64 year olds with physical or mental impairments) who are reported to be endangered (LA4Seniors.com). APS focuses on the victim's current and future safety. Reports of suspected or alleged abuse are recorded by mandated reporters on a *Report of Suspected Dependent Adult/Elder Abuse form*. (California Department of Social Services, 2000). APS social workers visit alleged victims to determine whether they are in danger. If the individual is in imminent danger, APS can remove the individual from his or her residence or place of harm. Otherwise, they try to eliminate or reduce the endangerment by providing necessary services, including follow-up and monitoring.

APS cannot investigate an incident without the victim's consent unless it involves a possible penal code violation. Welf. & Inst. Code § 15636(a). APS must report their investigation to law enforcement and request an investigation if the alleged perpetrator is to be prosecuted.

⁸ Assem. Bill No 430 (2001-2002 Reg. Sess.); Welf. & Inst. Code § 4427.5.

4. Long-Term Care Ombudsman

The Office of the State Long-Term Care Ombudsman was established by the California Department of Aging (CDA) pursuant to the federal Older Americans Act and the state Older Californians Act. 42 U.S.C. §§ 3001 et seq.; Welf. & Inst. Code §§ 9000 et seq. Its mission is to advocate for the dignity, quality of life, and quality of care for all residents in long-term care facilities. The federal Administration on Aging, which administers the Ombudsman program, has indicated that it is their long-standing policy that the Ombudsmen may serve individuals with disabilities who are living in long-term care facilities. 42 U.S.C. §3058g(a)(3). This includes persons with developmental disabilities under age 60.

Ombudsmen, who are mostly unpaid volunteers, serve as advocates for adult residents of long-term care facilities, investigating complaints and monitoring conditions and care in these facilities. Pursuant to State law, they also investigate allegations of abuse and neglect. Welf. & Inst. § 156050(a). Reports of suspected or alleged abuse are recorded on the same reporting form utilized by APS. When an Ombudsman receives a report, he or she is mandated to investigate the complaint to determine the validity of the report and refer it to the appropriate agency for further action as necessary. 42 U.S.C. § 3058g(a)(3); Welf. & Inst. Code §§ 9720(a) and 15650(f). With victim consent, the Ombudsman refers cases of abuse to APS or law enforcement for assistance. Welf. & Inst. § 15640(d). The Ombudsmen are mandated to refer cases of serious neglect to the appropriate licensing authority (e.g. Department of Health Services) and the Bureau of Medi-Cal Fraud and Elder Abuse. *Id*.

B. Title 17 – Special Incident Reports Regarding Regional Center Clients

While the Abuse Reporting Act places duties to report upon individuals, the California Code of Regulations place reporting duties on facilities providing services, including housing for persons with developmental disabilities. DDS requires the reporting of special incidents by facilities vendorized⁹ by the local regional centers. Cal. Code Regs. tit. 17 §54327(b). This special incident reporting system establishes a process for DDS and regional centers to monitor the

⁹ Vendors are facilities, programs or service providers authorized and funded by the local regional center to provide services to people with developmental disabilities.

health and safety of consumers in the community and to ensure quality services and supports are provided to individuals with developmental disabilities.

A special incident includes:

- 1. reasonable suspected abuse or exploitation, including physical, sexual, fiduciary, emotional/mental abuse, or physical and/or chemical restraint;
- 2. reasonable suspected neglect, including failure to provide medical care, to prevent malnutrition or dehydration, to protect from health and safety hazards, to assist with personal hygiene, or the provision of food, clothing, or shelter;
- 3. the death of any consumer;
- 4. cases in which a consumer is the victim of a crime;
- 5. cases in which a consumer is missing and the vendor or long-term health care facility has filed a missing persons report with law enforcement;
- 6. unplanned or unscheduled hospitalization, serious bodily injury, or accident; or
- unusual occurrences reportable to Department of Social Services (DSS) or Department of Health Services (DHS).

Id.

A comparison of the Abuse Reporting Act with these regulations reveals that there are variations in the definition of abuse and neglect. This means some incidents are reportable under the Abuse Reporting Act but are not considered special incidents requiring reporting to the regional center and vice versa. For example, isolation is considered abuse pursuant to the Abuse Reporting Act while it is not considered a special incident. Welf. & Inst. Code § 15610.43; Cal. Code Regs. tit. 17 § 54327(b). And conversely, Title 17 regulations include physical and chemical restraint in the definition of abuse while the Abuse Reporting Act has no comparable regulation. *Id*.

The regulations further outline the required elements of the report, which differ in form and content from the requirements under the Abuse Reporting Act. Each regional center has its own special incident reporting form for vendors to record reportable incidents. While there is some variability in the forms across regional centers, special incident reports prepared by regional centers are submitted electronically via DDS' Electronic Data Reporting System using a standard reporting field.

Upon receipt of a special incident report, regional centers review the report and decide what action is necessary. Title 17 mandates that regional centers make appropriate and timely referrals to authorized investigative entities. Cal. Code Regs. tit. 17 § 54327.1(b)(16). Regional centers also track any action taken by other entities, including the vendor, law enforcement, APS and licensing agencies. Id. The regional center forwards information about the special incident to DDS. DDS may require the regional center to follow up and submit additional information.

Each regional center is required to establish a Risk Management, Assessment and Planning Committee to ensure accurate and timely handling of special incidents. These committees review special incident reports to identify trends and unusual patterns. Cal. Code Regs. tit. 17, § 54327.2(b). DDS has contracted with the Columbus Organization to analyze the special incident reports for trends, conduct focused reviews, and develop prevention strategies. This analysis and statewide data on special incident reports are not publicly available.

C. Title 22 – Facility Reports to Licensing

Many facilities must also report incidents of abuse or neglect to their respective licensing agencies. For example, abuse occurring in an Adult Residential Facility, a long-term care facility, is reported to both the Ombudsman and Community Care Licensing (CCL). Typically facilities are required to report all unusual occurrences which threaten the welfare, safety, or health of clients. Other reportable events include the death of a resident, incidents which threaten the physical and emotional health or safety of a resident, any suspected physical or psychological abuse of a resident, and any injury to a resident requiring medical treatment. Cal. Code Regs. tit. 22, §80061(b)(1). According to the Department of Social Services (DSS), there are two specific forms available to licensees for reporting, one for "unusual incidents/injuries" and the other for deaths. These forms have spaces to indicate

other agencies or individuals notified. (Department of Social Services, electronic mail, May 30, 2003).¹⁰ The regulations do not specify who must report, and not all regulations specify what incidents must be reported and when.

Licensing may conduct its own investigation of an incident of abuse or neglect to determine if the facility violated any regulations. Violations may include failure of a facility to report an incident of abuse. If a regulatory violation is substantiated, the licensing agency may penalize the facility, issuing deficiencies or citations or suspending or revoking a facility's license.

¹⁰ Written comments to the final draft of this report received from the Department of Social Services.

A. Current reporting laws lead to inconsistent outcomes and inadequate protections for victims with developmental disabilities.

While intended to provide efficient reporting of incidents of abuse and neglect and to protect and support victims with developmental disabilities, the current set of rules and regulations is circuitous when implemented. One incident of abuse or neglect must be reported to different and independent entities, each with distinct reporting requirements. Incidents reportable under one set of regulations may not be considered a reportable event under other regulations.

Mandated reporters decide who to report an incident to and in what order. This initial choice determines the timeliness and quality of the initial investigation. Reports of crimes can be misdirected to a variety of administrative agencies, and either never referred to law enforcement or referred too late to prevent contamination of evidence, thus frustrating equal justice.

The system must ensure that when abuse, neglect and/or a crime involving a person with a developmental disability is suspected, the appropriate agencies are notified without delay. This is necessary to provide for immediate protection of the victim and a thorough, timely and competent investigation. Currently, when a report is made to an agency lacking jurisdiction, the abuse report is not taken and the caller is told to contact the appropriate agency. This creates a delay, at best, and ultimately discourages some from reporting.

Investigating agencies inconsistently share information about an investigation after initial notification. Because there is no designated entity with authority to oversee compliance with cross-reporting between investigating agencies or entities when it is required, there are limited assurances that cross-reporting is consistent and appropriate. Cross-reporting and systemic oversight of reporting would ensure all required agencies are notified promptly of incidents and responses to incidents involving this vulnerable population.

B. Mandated reporters in the disability service system are not uniformly aware of their reporting obligations.

Not all mandated reporters are fully aware of their multiple reporting obligations for many reasons. First, many facilities or agencies have an internal system of reporting suspected abuse or neglect that circumvents and may replace mandated reporting requirements. For example, a facility, by policy, may require a nurse to report suspected abuse or neglect via an internal incident report without contacting the appropriate investigative agency directly. This internal report moves through the facility's administrative channels before the appropriate investigative agency is contacted, leading to unnecessary delays in reporting and investigation. These policies mislead the mandated reporter about the satisfaction of their reporting duty. Another example of internal systems of reporting relates to reports made by vendors to the regional center. Regional center vendors (who are mandated reporters) have an obligation to also report incidents to the service coordinator of the regional center. However, many vendors believe they have met their reporting obligations when they report to the regional center. Furthermore, the inconsistency in definitions of reportable events between the Abuse Reporting Act and special incidents pursuant to Title 17 only further confuses mandatory reporters about their reporting obligations. These various policies and practices mislead personnel about their mandated reporting duties.

Existing mandated reporting training materials tend to focus on the elderly, misleading viewers about their reporting mandate for abuse or neglect involving victims with developmental disabilities. A recent example is the training videotape and curriculum about the reporting of elder and dependent adult abuse developed and distributed by the California Attorney General's Office, Department of Justice (DOJ) (Department of Justice, 2002). This training program, targeted at mandated reporters in long-term care, community care, and residential care facilities, reviews their reporting obligations pursuant to the Abuse Reporting Act. However, the tape focuses almost entirely on elderly residents. The phrase "dependent adult" is used only once during the video tape, whereas the terms "older adult" or "elderly" are used throughout. The tape contains a number of vignettes or case examples of abuse and neglect but none portrays a victim with a developmental disability under 65 years of age. Ultimately, the tape misleads the audience to only report abuse or neglect involving elderly victims and overlook their reporting obligations when the victim has a developmental disability. According to DSS, the DOJ has agreed to revise the video when funding is available. (Department of Social Services, electronic mail, May 30, 2003). However it is unclear when funding will be available.

Internal Reporting of Abuse

One caller to Protection & Advocacy, Inc. described an incident where a direct care provider at a large intermediate care facility threatened a resident with a cigarette lighter, in order to "persuade" the resident to take a shower. The victim sustained no physical injury but undoubtedly sustained emotional trauma, as did two peer witnesses. The care giver was fired but her whereabouts are unknown. As she was an unlicensed care provider, there are no safeguards warning future victims of her history of abuse.

According to the caller, this incident of abuse was handled internally without reporting to or involving outside investigators or the regional center. In fact, direct care staff at this facility were instructed to report all special incidents internally only, to the supervisors within the facility.

C. Many investigators lack expertise in conducting abuse and neglect investigations involving victims with developmental disabilities.

Under current law, at least six entities may investigate reports of abuse and neglect involving people with developmental disabilities: law enforcement, special investigators at developmental centers, APS, the Ombudsman, regional centers, and licensing agencies (for facilities and licensed care providers). The skill of investigators in these separate systems varies considerably, with many lacking sufficient training in interviewing victims with developmental disabilities. This causes inconsistent outcomes and unequal protection for victims with developmental disabilities, including failure to collect critical information from the victim about the incident and perpetrator, inappropriate assessments regarding the credibility of the victim, and ultimately, very few prosecutions of alleged perpetrators.

In addition, many first responders to a scene, other than law enforcement, may not receive relevant training in recognizing possible criminal conduct and identifying and preserving a potential crime scene and/or criminal evidence. Consequently, evidence of a crime may be contaminated or completely elude untrained investigators. It is notable that very few situations involving potential victims from the general population permit potential criminal conduct to be investigated initially by administrative agencies, as is the case with victims with developmental

disabilities. This represents a separate and unequal system of justice for crime victims with developmental disabilities.

1. Law Enforcement

Law enforcement has the most experience conducting investigations. While law enforcement is the designated agency to investigate crimes, the Abuse Reporting Act permits an election about which agency is contacted initially when the victim is a person with a disability. Many law enforcement departments describe receiving very few reports about crimes against people with developmental disabilities. In one large urban county, officers and detectives report that approximately 20% of their calls under the Abuse Reporting act involve people with disabilities (as compared with the elderly) and, of those calls, the majority involve allegations occurring in facilities, not in the community. This failing is important because law enforcement is the most appropriate entity to conduct investigations of criminal acts of abuse or neglect if the intent is to prosecute perpetrators.

Officers have minimal training in working with people with developmental disabilities. In the police academy, law enforcement officers are given a 6-hour course regarding people with mental and developmental disabilities. The bulk of their training specifically addresses intervening with persons with psychiatric disabilities in crisis in the community. Beyond this, officers are not required to receive any mandatory refresher instruction regarding this unique population of victims.¹¹ Victims with developmental disabilities express frustration in the response by law enforcement to their reports of abuse or neglect. Many say they did not report later crimes because of the poor response they received by law enforcement to a prior incident.

2. Special Investigators in Developmental Centers

The hiring criteria and training requirements of special investigators at developmental centers are below that required by most law enforcement agencies. While most community police officers must graduate from a 6-month program at the police academy, investigators at developmental centers are only required to

¹¹ In 2001, an eight hour advanced officer training course, entitled, Police Response to People with Mental Illness or Developmental Disabilities, was developed by the California Commission on Peace Officer Standards and Training (POST) in consultation with community, local and state organizations and agencies with expertise in the area of mental illness and developmental disabilities, along with consumer and family advocacy groups.

complete a 40-hour basic course in arrest, search and seizure. Completion of this training program is not a minimum job qualification but rather required within the first 90-days of employment. Although more training is expected within the first year of hire¹², there is no structured program to track compliance with initial training requirements or target continuing education needs to increase job proficiency of developmental center law enforcement personnel.

Developmental center law enforcement investigates both administrative (i.e. employment or personnel) and criminal matters. Allegations of abuse or neglect may implicate both administrative and criminal issues, but these investigations are rarely separated. This potentially jeopardizes the integrity of the criminal investigation by inadvertently compromising the admissibility of evidence obtained without the necessary admonishments or chain of custody safeguards.

A March 2002 investigation by the DOJ of the law enforcement program at the developmental centers found that officers' continuing professional training is insufficient, particularly specialized instruction in investigating abuse, sexual assault, and crime scene preservation and evidence collection (Department of Justice, 2002). Since release of the DOJ report, DDS has worked to implement an infrastructure to support accomplishing many of the recommendations, including hiring more experienced law enforcement officers for the Office of Protective Services at DDS headquarters. DDS acknowledges that many issues remain, including those related to officer training, recruitment and retention, and the separation of administrative and criminal investigations.

¹² Investigators at developmental centers not possessing a POST certification as a peace officer are required to complete a POST course regarding arrest, search and seizure, and firearms training. Within the first year of employment, officers are further required to attend the Specialized Investigators' Basic Course, a 591 hour program regarding criminal investigations.

Incomplete Reporting of Abuse

Chuck Waters was a 29-year-old resident living in a state developmental center. In January 2001, Mr. Waters became agitated, destroying property and attempting to push and strike staff. Two staff members grabbed Mr. Waters' arms. He resisted, turning and pulling against the staffs' hold. Two other staff were summoned and Mr. Waters was taken to the floor in a prone containment. During the containment, a "pop" sound was heard. A subsequent x-ray revealed that Mr. Waters had sustained a spiral fracture of his arm.

Staff notified the Senior Special Investigator who conducted a thorough and timely investigation. He found that staff had used an improper restraint technique which caused the fracture. Three of the four staff members involved in the restraint were not currently certified in restraint procedures.

The developmental center never reported the incident to the licensing agency (DHS) as required. DHS learned of the incident coincidently during their licensure survey but did not conduct a separate investigation. No deficiency or citation was issued by DHS for the injury or the facility's failure to report the incident.

3. Adult Protective Services

APS uses social workers to conduct investigations with the focus on endangerment of the victim. The experience of APS investigators in working with people with developmental disabilities varies. Interviews with key APS staff suggest that they lack expertise in working with people with developmental disabilities and frequently refer cases involving an individual with a developmental disability to regional centers. Some offices employ outside experts or consultants to provide training and consultation. Others work with the regional center to assess a particular situation and provide assistance.

4. Long-Term Care Ombudsman

Initially, Ombudsmen receive 36 hours of in-class mandatory training; the majority of the training focuses on elder issues and the dynamics of aging, and pertains primarily to issues other than conducting abuse and neglect investigations, such as the Ombudsman's role and responsibilities, effective communication and interviewing techniques, residents' rights, and the long-term care setting. After classroom training is complete, the CDA reports Ombudsmen participate in an

internship with an "experienced" Ombudsman before resolving complaints and investigating abuse allegations on their own. The length of the internship varies, depending on the needs of the trainee. Certified Ombudsmen must also complete 12 hours of continuing education annually. (Department of Aging, personal communication, May 16, 2003).

Three areas of concern arise around the Ombudsman's role in investigations of abuse or neglect allegations. First, Ombudsmen respond to a broad range of issues and relatively few of their cases involve allegations of abuse. The Office of the Long-Term Care Ombudsman reports that less than 15 % of complaints received in 2002 involved allegations of abuse or neglect.¹³ On average, Ombudsmen work only 20 hours per month with some working a more reduced schedule. (Department of Aging, personal communication, August 11, 2003). APS personnel, who respond to abuse allegations in the community, generally work full-time, with the majority of their caseload involving abuse or neglect.

Second, because of limited training and experience in working with individuals with developmental disabilities, some Ombudsmen may not be able to readily identify or verify abuse reports. In spite of recent changes in training curricula incorporating how to investigate cases of abuse of persons with developmental disabilities, the CDA acknowledges that additional training is needed. (Department of Aging, personal communication, July 10, 2003).

Finally, according to the CDA, the Ombudsman investigates cases of suspected abuse of residents in long-term care facilities, including persons with developmental disabilities under age 60, and refers cases to the appropriate licensing authority for further action. (Department of Aging, personal communication, May 16, 2003).¹⁴ However, other reliable sources report that, in some cases, the Ombudsman does not investigate abuse or neglect allegations involving persons with developmental disabilities and these are referred directly to DDS, who, in turn, refer the investigation to the regional center. If this circumstance is correct, this may create an unnecessary delay in response.

¹³ In the year 2002, a total of 34, 000 complaints were received Five thousand (5000) involved complaints of abuse or neglect. (Department of Aging, personal communication, July 10, 2003).

¹⁴ Written comments to the final draft of this report received from the Department of Aging.

Opposing Outcomes to One Abuse Allegation: Who was the Victim?

Dan Casey is a 30-year-old man with developmental and psychiatric disabilities and was living temporarily in a crisis facility. He has limited verbal abilities. One morning facility staff insisted on using the client restroom adjacent to Mr. Casey's bedroom, in violation of facility policy. Mr. Casey became angry and an altercation ensued between Mr. Casey and three facility staff. Mr. Casey alleged that staff struck him repeatedly with a heating grate, threw him down, and kicked him. He sustained multiple injuries, including bruises to his face and torso and parallel lacerations to his abdomen consistent with injuries from a heating grate. Facility staff claim that Mr. Casey's injuries were sustained as they attempted to restrain him. The facility terminated all three employees.

Law enforcement conducted an investigation, including an interview of Mr. Casey, the alleged perpetrators, and two staff members not present at the time of the altercation. Police concluded that Mr. Casey was the perpetrator and misdemeanor assault charges were filed against him.

CCL also conducted an investigation. They determined Mr. Casey to be the victim of abuse and cited the facility for failing to provide for the care and safety of Mr. Casey. CCL prohibited the three employees involved in the incident from working in a CCL licensed facility.

5. Licensing Agencies (Community Care Licensing, DHS, Provider Licensing Boards)

Licensing bodies are mandated to investigate whether facilities violate regulations. As a result, their investigation focuses on the facility's culpability in and response to the underlying incident. Investigations conducted by licensing bodies are not directly related to protection of the individual victim but may result in new safeguards for remaining residents.

There is considerable variability in the quality and timeliness of investigations and the training of individual investigators in working with victims with developmental disabilities.¹⁵ For example, CCL Program Investigators have peace officer status

¹⁵ According to DSS, training on investigation of adult/elder abuse complaints is currently being provided to all CCL analysts and managers with adult and elderly residential caseloads. This training includes components that provide interviewing and investigation techniques that are specific to clients with developmental disabilities. CCL analysts with caseloads serving clients with developmental disabilities are also required to attend an initial 24-hours of core training on the needs and characteristics of persons with developmental disabilities followed by annual 24-

and are responsible for the investigations of high priority complaints such as abuse. (Department of Social Services, electronic mail, May 30, 2003). Investigators from other licensing bodies do not have similar peace officer status.

If the alleged perpetrator is a licensed care giver, an investigation may also be conducted by their licensing board, if notified. The variability and lack of training described elsewhere is also reported with these investigators.

6. Regional Centers and DDS

While regional centers and DDS have no duty to investigate, regional center caseworkers reportedly investigate referrals from the Ombudsman and monitor the status of investigations conducted by other entities, including those listed above. Regional center staff receive periodic training on investigating alleged regulatory violations but many lack specific expertise in conducting abuse investigations.

7. District Attorneys and Judges

Prosecutors typically do not receive any special training in working with people with disabilities (Ventura County District Attorney's Office, personal communication, July 11, 2002). It is incumbent upon the prosecutor to utilize all resources available to prosecute their case, including petitioning the judge for special accommodations and evidence code adjustments that are needed to assist the victim or witness with a developmental disability. Yet, not all prosecutors or judges understand and pursue the accommodations necessary for an individual with a cognitive impairment. All personnel in the criminal justice system should understand the needs of victims and witnesses with disabilities and the related accommodations needed to provide them equal access to the criminal justice system.

There have been some advances in recent years regarding the inadequate protections and treatment of individuals with disabilities who have been victims of crime by the criminal justice system. While these programs attempt to address some of the gaps identified in this report, they are frequently short-lived due to temporary funding and not uniformly available throughout the state.

hour advanced training courses. Some of the topics covered include interviewing skills, communication systems, active-listening and recognizing indicators of abuse. (Department of Social Services, electronic mail, May 30, 2003).

Rape Victim Denied Equal Justice

Leslie Vales is a 26-year-old woman living independently. As Ms. Vales was going to her sheltered workshop, a male stranger approached her at the bus stop. The perpetrator grabbed her and dragged her across the street into some bushed. He allegedly raped her twice and then sodomized her. After the assault, Ms. Vales got up, quickly dressed herself, and ran to catch her bus.

When she arrived at her workshop, Ms. Vales immediately reported the rape to staff. A sexual assault examination showed evidence of trauma, including leaves and sticks inside her vagina. Based upon a description of the assailant and location information provided by Ms. Vales, law enforcement quickly apprehended the perpetrator. He confessed to having sex with her.

At trial, many, of the prosecutor's requests for accommodations were denied. Evidence of Ms. Vales' disability (IQ of 59), which would help jurors understand its impact on her testimony, was excluded. Evidence that she was a dependent adult could have extended the perpetrator's sentence, if convicted. The defense attorney asked leading, compound, and complex questions and used complicated medical terms.

Ultimately, Ms. Vales gave seemingly inconsistent answers. In the end, the jury was unable to reach a verdict and the perpetrator was not convicted.

D. California has no coordinated database that documents the extent and severity of abuse, neglect, and victimization of people with developmental disabilities.

There are no statistics publicly available regarding the incidence of crime, abuse, and neglect of individuals with developmental disabilities and the system's response. Existing agency data collection systems do not use common data elements so they are not compatible and cannot be merged or compared to track the response. It is difficult to tract an initial report through the criminal justice system to arrest, prosecution and conviction and there is no aggregate information publicly available.

DDS and regional centers keep records on the occurrence and response to special incidents. These data could help to approximate the incidence of abuse, neglect, and response to crimes involving people with developmental disabilities. Currently

these data are only utilized for internal monitoring, including statewide data analysis and monitoring by an independent contractor (the Columbus Organization) for DDS, and are not available for public scrutiny.

APS collects statewide data on incidents involving elders or dependent adults. This information is publicly available but does not specify type of disability. As the Ombudsman may not investigate allegations involving persons with developmental disabilities, the data complied by this agency does not offer sufficient information regarding the victimization of this population.

Law enforcement reporting records do not specifically indicate if an individual has a disability, unless the report is related to "domestic violence" or covered by the Abuse Reporting Act. As with APS, data collected by law enforcement pursuant to the Abuse Reporting Act does not delineate type of disability. It only indicates that the criteria for a dependent adult had been met. There is no mechanism by which incidents investigated by law enforcement are tracked through the criminal justice system.

Agencies, policymakers and advocates cannot calculate the rate of prosecutions and convictions for perpetrators of crimes against victims with developmental disabilities accurately. This hampers the ability to direct reform efforts targeting deficiencies in the criminal justice system and evaluate the effectiveness of new programs.

Finding I Abuse and neglect of people with developmental disabilities is a serious public policy issue warranting the highest level of attention.

The literature indicates that abuse and neglect of people with developmental disabilities is a pervasive problem nationwide, and California likely mirrors the national problem. Individuals with disabilities are victims of abuse and neglect more frequently than the general population. Individuals with cognitive impairments (e.g. persons with developmental disabilities) are at greatest risk. Yet the abuse response system has failed to implement a program that properly prioritizes this public health problem. It has failed to accurately document the scope of the issue or to develop sufficient initiatives that decrease the frequency of occurrence and increase protections to victims.

There is no reliable statewide system in California that documents the frequency of abuse or neglect of individuals with developmental disabilities. Each entity in the abuse response system has a singular data collection system. Much of the data gathered fails to distinguish victims by type of disability and is not shared with other entities in related systems. With so many players (DDS, regional centers, APS, law enforcement, Ombudsman), any individual agency's data likely portrays only a portion of the picture of abuse and neglect of individuals with developmental disabilities.

Without accurate, specific, publicly available data, there is no means of quantifying the extent of the problem, isolating specific gaps in the abuse response system, or ensuring that individuals and entities have fulfilled their obligations. Even more importantly, there is little incentive to fund programs because the extent of the problem has not been determined. Furthermore, the outcome of new programs or reform initiatives cannot easily be measured.

To date, no single agency is championing the issue and coordinating reform efforts. No single agency has emerged to take responsibility for documenting and tracking individual incidents of abuse and ensuring that victims receive necessary services and protections. While the California Health and Human Services (HHS) Secretary, Grantland Johnson, put forth extensive efforts to positively impact this critical problem through the Crime Victims with Disabilities Initiative (CVDI)¹⁶, its authority and sustainability was limited by statutory and budget constraints. By statute, HHS has jurisdiction over a select group of state departments, which does not include criminal justice or judicial entities. Due to a severe state budget crisis, the State was unable to continue the CVDI. Without a designated office assuming responsibility for this issue and tracking incidents through the abuse response system, abuse and neglect of individuals with developmental disabilities is likely to continue.

Recommendation 1: Eliminating abuse and neglect of people with developmental disabilities must be made a public health priority in California.

The incidence of abuse and neglect of individuals with developmental disabilities is significant. These victims are members of a vulnerable population less able or equipped to defend themselves. Most are victimized by the very individuals identified to care for them. Inattention by state agencies and the Legislature has allowed this issue to linger too long. The complexity of the system and related deficiencies demands sweeping statewide systemic reform. What constitutes the appropriate response of society and systems working with citizens with developmental disabilities, without unduly suppressing choice and self-direction, is the ultimate challenge for system change. Reform must become a top priority for the Governor, lawmakers, the criminal justice system, and the agencies responsible for providing services and supports to persons with developmental disabilities.

Recommendation 2: The Legislature must designate a lead agency with authority and responsibility to coordinate system reform.

Given the extent of the issues identified, the Legislature must designate one agency with the authority and responsibility for coordinating reform measures. This agency must possess sufficient authority to assure a coordinated system of services that will significantly reduce the risk of victimization and unequal access to justice for victims. Regular contact and input from agencies, statewide associations, and advocacy groups must be solicited and considered. Annually, this agency must submit a report to the Legislature including, but not limited to, data about incidents of abuse against people with developmental disabilities and the response from

¹⁶ For a complete overview of this initiative see Appendix B Recent Advances, page 39.

DDS, law enforcement, APS, and the Ombudsman until their role in the abuse response system ceases (see Recommendation 5).

Recommendation 3: An integrated data collection system must be implemented to:

- document the incidence of abuse and neglect; and
- track the outcomes of criminal investigations and prosecutions.

Data from California's criminal justice and developmental disabilities systems do not provide a clear picture of the incidence of abuse, neglect, and victimization of people with developmental disabilities. Without accurate data there is no mechanism to:

- monitor the severity of the problem,
- identify areas of significant need for immediate and sustained intervention,
- guide the systematic development of services and supports, which will ultimately lead to environments which do not put people with developmental disabilities at excessive risk for harm, and
- evaluate the outcomes of interventions and institutional reform.

A uniform statewide data collection system must be developed which will address these issues. Such a system must have the following characteristics:

- All reporting forms (used by law enforcement, APS, DDS, CCL, etc.) must have a field which identifies whether the victim has a disability and should utilize uniform terms and definitions related to the presence and type of disability.
- Outcome data on crimes reported must be collected documenting the results of investigations, prosecution, and judicial determinations.
- Data from parallel systems which are involved when a victim has a developmental disability (regional centers, APS, law enforcement, CCL) must be relational (i.e., the database is built so that data related to individual victims from all systems involved can be integrated).
- Appropriate protections must be put into place to protect the identity of victims.
- Analyses of data in aggregate form must be reported and available for public scrutiny.

Finding II The current system of protection is inadequate for victims with developmental disabilities.

The current abuse reporting and response system involves a multitude of regulatory and investigative agencies, each addressing a different component. A single allegation may involve notifying a minimum of four agencies, each with a separate focus and with little interagency collaboration or cooperation in practice. Frequently, the investigator varies depending on where the individual lives (e.g., law enforcement or APS for community residents; Ombudsmen for residents of long-term care facilities; developmental center investigators for residents of developmental centers), leading to variation in investigative practices and stimulus to investigate. In addition, communication between and among agencies is not well-coordinated.

Reporters with good intentions may inadvertently fail to report allegations to each agency, thinking they have met their mandated reporting requirement at the first report. While there have been efforts to provide better training to mandated reporters, most efforts frequently emphasize reporting obligations for cases of elder abuse or neglect, with less attention given to reporting duties for incidents involving individuals with developmental disabilities.

There is no one entity accountable for the appropriate investigation of all incidents involving people with developmental disabilities. Consequently, incidents are under-reported and perpetrators may escape punishment, free to repeat acts of violence and other criminal activity. People with developmental disabilities are less safe than the general citizenry.

Even when identified, perpetrators are poorly tracked by the system. Currently, several licensing bodies oversee the various professionals, paraprofessionals, and technicians that work with people with disabilities in the community, at home, and in hospitals and developmental centers. Each licensing body has a procedure by which consumers or providers may check the status of an individual care giver's license. In some systems care giver information is accessible only by social security number and not individual name, frustrating public access. But many complain investigations lag for months with the individual still eligible to work. This allows perpetrators opportunities to continue to victimize individuals under their care. Ultimately, the system is only as good as the current status of its

database. Newspaper accounts allege that the California Medical Board's records are inadequately maintained (San Francisco Chronicle, 2002). The 2002 review of over 60 widely reported verdicts and arbitration awards against doctors revealed that one third were missing from the agency's public database.

Perhaps, the most comprehensive background check requirement is that mandated for all community care facilities licensed by the DSS. According to DSS, the background check is not a point in time clearance because DSS continuously receives subsequent information from the DOJ on all individuals for which a background check is requested (until the DOJ is notified otherwise). This means that if a person who is currently working in any community care facility is subsequently arrested or convicted, the DOJ notifies DSS. DSS does not verify criminal background clearance during annual visits because DSS is confident that they are aware of all subsequent criminal activity. Similarly, DSS permits an individual to request that his or her clearance from one facility be transferred to another licensed facility when they change employment rather than requiring a preemployment check by the new facility. Though DSS processes the clearance transfers and maintains records of individual's criminal histories, providers are required to maintain copies of clearances, transfer approvals and criminal record exemptions in the individual's file at the facility. (Department of Social Services, electronic mail, May 30, 2003).

Only individuals who have been arrested or convicted are entered into the system. As has been noted throughout this report, most perpetrators accused of crimes are never formally reported to law enforcement. The accusation is often handled administratively, typically resulting in the termination of the employee. As a result, many perpetrators move to other facilities to continue predator activity. The current system must eliminate administrative handling of accusations of abuse and criminal activity, assure the full implementation of existing policies where they exist and ensure pre-employment criminal background checks are required of all care-providers regardless of setting.

Care Givers' Prior history of Abuse

Jeanne Swain was a 22-year-old non-verbal woman with autism. She was living in a small licensed adult facility. Ms. Swain was found by care staff seated in a bathtub full of scalding hot water. She sustained 2nd and 3rd degree burns over 30% of her body. Staff were unable to explain how she got into the bath unsupervised or why was the water so hot. Ms. Swain died several weeks later of complications from her burns.

Investigations revealed that the 16 of the 18 employees employed by the home in the previous year had criminal records. A child abuse allegation had been substantiated two months earlier against the staff member on duty at the time Ms. Swain sustained her lethal burns.

Recommendation 4: Regional centers must have an increased and uniform role in coordinating the response and services provided victims.

Given the complexity of the reporting system, it is imperative that a single agency ensure that all necessary entities are contacted and fulfill their individual duties. Regional centers are uniquely positioned to play a pivotal role in ensuring a timely and thorough response by all entities to allegations of abuse and neglect of individuals with developmental disabilities. This is evidenced by the regional center's dual role in service procurement and service coordination. As part of their responsibilities related to service procurement, regional centers are charged with monitoring the quality of service provided by their community vendors, including the vendor's response to a special incident. The regional center's role in service coordination goes beyond the coordination of specialized developmental services. It includes all community services afforded to the general public regardless of disability, commonly referred to as generic services.

The regional center's role must be expanded to ensure that entities in the abuse response system are notified and complete their associated duties. For example, if a vendor notifies the regional center of an incident of suspected abuse, the regional center can ensure that law enforcement is notified and conducts a thorough and timely investigation. The regional center can offer assistance to law enforcement when interviewing the victim and can caution them not to rely solely upon the statements of facility staff. They can also ensure that the vendor receives follow-up training and is compliant with their mandated reporting obligation. Vendors who fail to protect clients adequately or consistently fail to comply with their reporting duties would enter into a plan of correction with their regional center, agreeing that no referrals can be made to the vendor until all terms in the agreement are met.

Since regional centers are already required to have expertise in criminal justice and forensics, this person should also be responsible for meeting this recommendation. Over time, this individual will cultivate relationships with other entities and increase the efficiency of the system's response. He or she will be able to identify trends - successes and inadequacies in the abuse response and criminal justice systems. Future victims will benefit from this accumulation of experience. Regional centers can also implement proactive initiatives to improve the system and better serve the needs of their consumers.

Following an incident of abuse or neglect, regional centers can work with victims in a variety of ways. In addition to crisis intervention and coordination of victims' assistance services, the regional center can take a preventive approach. This should include training in abuse prevention and providing adequate support to consumers. While this training should make very clear that the individual is not to be blamed for becoming a victim of a crime, it should also discuss an individual's responsibility associated with personal choice and the potential to improve choices for desired outcomes. Regional centers may identify an array of housing options that allow individuals in unsafe situations to move easily and comfortably to another community-based setting, without the threat of institutionalization as the only alternative to tolerating abuse. Merging this model of prevention services seamlessly with crisis intervention and victims' assistance services will likely reduce the vulnerability of individuals with developmental disabilities and increase the responsiveness of entities within the abuse response system.

Recommendation 5: Incidents of abuse or neglect in long-term care facilities must be investigated by law enforcement or APS, not the long-term care Ombudsman.

Methods and systems for investigating abuse or neglect should not vary depending upon where the victim lives. These options should be changed to require reporting to APS or local law enforcement *only*. By assigning to APS and law enforcement the role of investigating abuse or neglect, the system is simplified and residents with developmental disabilities in long-term care facilities are better protected. Ombudsmen provide a valuable service to all residents of long-term care facilities. They monitor conditions and care in the facility and respond to a wide spectrum of resident complaints. As previously discussed, the Ombudsmen are primarily unpaid volunteers who work limited hours. Currently their training, experience and the focus of their work does not provide them with the level of expertise and skill in identifying and investigating abuse allegations comparable to APS or law enforcement. The Ombudsman's training and experience is focused primarily on issues of the elderly with very little existing training involving conducting abuse and neglect investigations involving victims with developmental disabilities. The Ombudsman's role in investigating complaints involving residents with developmental disabilities should cease.

However, given the Ombudsmen's continuing presence and advocacy role in longterm care facilities, they should receive additional and on-going instruction in identifying abuse, neglect, and criminal activity which will facilitate appropriate reporting to APS and local law enforcement for investigation. This training should also prepare them with skills to assure crime scene preservation which is critical to potential successful prosecution of perpetrators.

Recommendation 6: Victims with developmental disabilities must be provided new protections from perpetrators.

The balance between protecting victims' rights and the rights of alleged perpetrators must be carefully considered. However, when individuals are vulnerable and at exceptional risk or victimization, enhanced systems to respond to all allegations of abuse and criminal activity must be established and enforced. Without such a system, perpetrators will continue to escape prosecution, background checks will not be useful, and serial perpetrators will continue to prey on people with disabilities. Such enhancements require a number of changes in the current system.

Legislators must direct the lead agency to explore the following issues and potential solutions. The lead agency must (1) eliminate the internal handling of accusations of abuse and criminal activity by facility administration; (2) develop a system to periodically review employee terminations to determine if termination was due to potential allegations of abuse or criminal activity, (3) consider solutions to employer disincentives to report a thorough employee work history upon inquiry by a potential new employer; (4) establish a system which ensures consistent recording and monitoring of the arrest and/or conviction of perpetrators (including

but not limited to new fingerprint clearance for all newly employed care providers) and easy access of this information by future employers; (5) assure that all consumers have access to training and assistance in checking with local authorities to verify criminal record clearance for services such as supported living, independent living, or in-home supportive services and; (6) assure that the cost for background checks should not be a deterrent to obtaining this information.

Recommendation 7: The Department of Developmental Services must continue to implement the Department of Justice recommendations regarding the law enforcement division of developmental centers.

Allegations and incidents of abuse and neglect occurring in developmental centers are documented by facility staff and referred to law enforcement personnel employed at the centers. Inadequacies of this system are being addressed currently in response to recommendations made by the DOJ. DDS must continue to focus resources to the remaining issues. These include separating of criminal and administrative investigations, ensuring that criminal investigations take precedence, expanding the number of personnel in the law enforcement division, implementing standard procedures for the investigation of incidents, and reporting them to outside agencies, including local law enforcement. In addition, the basic training and continuing education of Senior Special Investigators must more closely proximate that of other peace officers. Finally, the qualifications of investigators hired must be raised to approach standards required by local law enforcement.

Finding III

Individuals within the abuse response and criminal justice systems lack training and expertise in working with people with developmental disabilities.

Investigators and individuals within the criminal justice system are generally inadequately trained in working with individuals with developmental disabilities. Victims, family members and advocates report lapses in the criminal justice system when investigators lack skills in communicating with and providing accommodations to individuals with developmental disabilities. APS and law enforcement do not receive adequate initial and periodic retraining regarding how to work with this unique and vulnerable population. Law enforcement officers only receive limited training in the academy and it focuses primarily on individuals with psychiatric disabilities. Ombudsmen receive minimal training regarding working with individuals with developmental disabilities. This results in investigations of variable quality with inconsistent outcomes, ultimately leading to inadequate protection of victims with developmental disabilities and low rates of prosecution of alleged perpetrators.

Encounters with the criminal justice system can be baffling and intimidating to people with cognitive impairments. Investigators and prosecutors may see victims with developmental disabilities as poor historians. The veracity of victims is often questioned. This leads to inadequate investigation, including failure to consider the testimony of victims sufficiently. Less egregious acts or acts where the mental capacity of the victim is considered a factor are often not reported to or aggressively investigated by law enforcement.

Investigators tend to rely upon information provided by facility staff and neglect to gather or sufficiently value necessary information from the victim or other witnesses with disabilities. Often facility staff have a conflict of interest in acknowledging that the incident occurred. Furthermore, the perpetrator is often a care giver and a member of the facility's staff.

Some prosecutors are reluctant to prosecute cases because of unfamiliarity with persons with developmental disabilities and the challenges posed by bringing such a case. Many judges have limited understanding about the needs of these victims and may narrow the application of courtroom accommodations to physical disabilities without similar consideration of cognitive disabilities. The result is failure by the criminal justice system to provide equal protection to victims with developmental disabilities and to offer them the same protections and response as victims of the general population.

Family Claims Law Enforcement Bias

Casey family members (see vignette on p.21) report that the investigation conducted by law enforcement was inadequate and biased against their son. They claim that officers assumed that Mr. Casey was the assailant, not facility staff, because he exited the home holding the weapon (a heating grate). Law enforcement allegedly disregarded Mr. Casey's explanation that he was holding the grate to show officers the weapon used to inflict his injuries. Law enforcement recorded a detailed and lengthy statement regarding the altercation given by the manager of the facility who was not present at the time and did not witness the altercation between Mr. Casey and three staff.

Recommendation 8: All agencies involved in the abuse response system must receive mandatory training regarding working with individuals with developmental disabilities.

Law enforcement must be required to periodically and regularly complete the California Commission on Peace Officers Standards and Training (POST) eighthour advanced officer training course, entitled, *Police Response to People with Mental Illness or Developmental Disabilities*. Similarly, there must be periodic training provided to local prosecutors and judicial personnel specifically regarding crimes against persons with disabilities, including requesting and providing necessary accommodations. APS and licensing agencies (for facilities and licensed care providers) should develop and implement a similar training component regarding conducting investigations involving victims with developmental disabilities.

Appendix A Definitions

There are a number of laws and regulations pertaining to the reporting and investigation of abuse and neglect allegations, primarily the Elder Abuse and Dependent Adult Civil Protection Act (the Abuse Reporting Act) and the California Penal Code. Each offers slightly differing definitions, which, in itself, presents problems because a specific incident may constitute a reportable event leading to different system responses depending on the governing regulations for the system responding.

Physical abuse, defined by reference to the California Penal Code, is any act involving assault, battery, assault with a deadly weapon or force likely to produce great bodily injury, and sexual assault including sexual battery, rape, incest, sodomy, and oral copulation. Welf. & Inst. Code § 15610.63. Citing the vulnerability of the victim to understand or report criminal conduct or to testify in court proceedings on their own behalf, the Legislature specified that certain acts of abuse or neglect of dependent adults rises to the level of criminal behavior, punishable with a fine and/or imprisonment. Penal Code § 368(b)(1). Sanctions include imprisonment for up to one year, or a fine of up to six thousand dollars (\$6,000), or both a fine and imprisonment. *Id*. Additional terms in state prison are added if the victim suffers great bodily harm from the offense. Penal Code § 368(b)(2). Circumstances not likely to produce great bodily harm or death but resulting in unjustifiable physical pain or mental suffering are considered misdemeanors. Penal Code § 368(c).

The Welfare and Institutions Code which regulates services for individuals with developmental disabilities, defines physical abuse as unreasonable physical constraint, prolonged or continual deprivation of food or water and the use of physical or chemical restraint or psychotropic medication for punishment, for a period of time beyond or for any purpose not authorized by the ordering physician. Welf. & Inst. Code § 15610.63.

Neglect is defined as the negligent failure of any person having the care or custody of a dependent adult to exercise that degree of care that a reasonable person in a like position would exercise and specifically includes failure to:

- 1. assist with personal hygiene;
- 2. provide food, shelter, and clothing;

- 3. provide medical care for physical and mental health needs;
- 4. protect from health and safety hazards; or
- 5. prevent malnutrition or dehydration.

Welf. & Inst. Code § 15610.57.

Appendix B Recent Advances

Efforts over the last several years to raise the awareness of the abuse response and criminal justice systems of the inadequacies of protections and treatment of people with disabilities have yielded some advances in the training of personnel. However, current budget issues have jeopardized some of these programs.

The State Council on Developmental Disabilities funded "Striving for Justice – Enhancing Services for Crime Victims with Developmental Disabilities", a statewide multidisciplinary conference organized by the Ventura County DA's Office. The conference, attended by more 150 law enforcement personnel, prosecutors, care providers, consumers and families, and others, was well-received. This DA's Office also developed a local law enforcement protocol to assist officers who encounter victims of crime, witnesses, and defendants with developmental disabilities. The California Attorney General's Office developed "Crime Victims with Disabilities, a Prosecutor's Guide to the California Statutes" which made its public debut at the conference and serves as an excellent companion resource to the training received and will benefit California consumers. This publication includes statutes and relevant case and other information helpful in trial preparation and requesting accommodations and was sent to District Attorneys throughout the State.

Beginning in 2002, the DDS instituted a comprehensive community-based risk mitigation and management system that is supported by an investment of approximately \$12 million annually. The system is comprised of three key components: (1) revised and expanded special incident reporting regulations, (2) a statewide electronic regional center special incident reporting (SIR) system, and (3) engagement of a contractor (Columbus) to perform independent risk mitigation and management services. The system operates on both a statewide and local regional center level. The SIRs the regional centers report to DDS through the State's electronic reporting system are the foundation of the system. This data is analyzed on a statewide basis by Columbus, and on a local basis by the regional center, to identify trends and strategies to prevent and/or mitigate consumer risk. Each regional center is now required to establish a Risk Mitigation and Management Committee and develop a Risk Mitigation Plan pursuant to applicable Title 17 regulations. Through Columbus, a quarterly newsletter addressing prevention and risk mitigation activities is published and distributed, and an information website (www.ddssafety.net) for consumers, families, service

providers, clinicians, and regional center staff is updated monthly. Annual training sessions for regional center staff, literature reviews, and routine SIR trend analyses are also provided by Columbus. This comprehensive system provides the DDS information and data reportedly from which to plan new initiatives and address issues of public policy in its efforts to protect consumers' health and safety and to their quality of life.

Pursuant to AB 1499 and AB 1690, each long-term health care facility¹⁷, community care facility¹⁸, and residential care facility for the elderly¹⁹ is required to provide training in recognizing and reporting elder and dependent adult abuse. Welf. & Inst. Code § 15655. According to DSS, training materials include the DOJ video tape and accompanying printed material. Staff are required to sign a statement acknowledging that they are mandated reporters of abuse. CCL is responsible for verifying training is completed. (Department of Social Services, electronic mail, May 30, 2003).

The Crime Victims with Disabilities Initiative (CVDI), funded beginning in 2000, addresses the issue of violent crimes against people with disabilities including: (1) assisting crime victims with disabilities; (2) providing training programs on personal safety and prevention, risk reduction strategies, and detection and reporting of crimes; (3) creating a public information campaign regarding violent crimes against people with disabilities; (4) funding six Crime Victims with Disabilities Specialist pilot programs throughout the State; and (5) under the direction of the California Health and Human Services Agency, approved plans developed by the departments of Aging, Rehabilitation, Developmental Services, Mental Health, Health, and Social Services for addressing crimes against their constituents with disabilities, including comprehensive manuals and training from the top down throughout each department. The Crime Victims with Disabilities Specialist pilot programs train and directly assist law enforcement and other agencies within the criminal justice system when a victim of a crime has a disability. These programs are expected to increase the reporting and investigation of crimes involving people with disabilities. They represent a concerted effort to

¹⁷ Long-term health care facilities include skilled nursing facilities, intermediate care facilities, nursing facilities, and pediatric day health and respite care facilities. Health & Safety Code § 1418.

¹⁸ Community care facilities include residential facilities, adult day programs, therapeutic day services facilities, foster family agencies and homes, small family homes, social rehabilitation facilities, community treatment facilities, and transitional shelter care and housing placement facilities. Health & Safety Code § 1502.

¹⁹ Residential care facility for the elderly means a housing arrangement where varying levels and intensities of care and supervision, protective supervision, or personal care are provided. Health & Safety Code § 1569.2.

enhance the criminal justice system's response to crimes against people with disabilities and the eventual increased prosecution of predators. This program was not included in the Governor's budget for FY '03-04 and all programs will cease.

Individual regional centers statewide have criminal justice projects and programs which address some of the problems identified in this report. Some regional centers have established resources for victims of crime, including purchasing crime victim recovery services. There are five forensic projects, which focus primarily on offenders with developmental disabilities. While these programs are assisting regional center clients accused of crimes, many of the same barriers confronting offenders are faced by victims.

In 2001, an eight hour advanced officer training course, entitled "Police Response to People with Mental Illness or Developmental Disabilities," was developed by POST in consultation with community, local and state organizations and agencies with expertise in the area of mental illness and developmental disabilities, along with consumer and family advocacy groups.

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