

Breaking the Silence: A Study of Abuse and Neglect of Individuals with Developmental Disabilities

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Introduction

The paper is derived from a national study of abuse and neglect of individuals with development disabilities. The paper is based on the survey results obtained from all fifty states and the District of Columbia. The purpose is to interpret the current situation for individuals with developmental disabilities in view of the following factors: the structure of service provided by each state and the procedure each state uses to define abuse and neglect, as well as record and report of existing data.

To date, there are limited national studies on abuse and neglect of individuals with developmental disabilities, which stems from the fact that there is limited national data and reports on this issue. Research conducted thus far stems from local, state, or regional sampling which is extrapolated or generalized to estimate, among other factors, the prevalence of abuse and neglect. Such data extrapolated from regional studies, case-control studies, or cross-sectional analysis provides representative subset data at defined times. However, while this type of research serves important descriptive and explanatory functions, it does not provide the type of reliable evidence needed to inform programmatic policy development overtime. With regional extrapolated data researchers can infer national prevalence rates for abuse and neglect, but these inferences will not include data on confounding factors that affect variants across regions overtime. Only a uniform national reporting system with sustained long-term data collection can inform prescriptive measures to address abuse and neglect in a systematic way. An example of such national data system is the one used by federal agencies such as the Department of Justice who have not only created specific policies initiatives to address domestic violence and child abuse, but have gained support, appropriations, and the ability to evaluate progress. An assessment of national and state capacity to address abuse and neglect of individuals with developmental disabilities in uniform manner was a primary catalyst for this report.

Due to the breadth and complexity of issues underlying this topic, I narrowed the focus of this report to data and information on abuse and neglect of individuals classified as developmentally disabled. I surveyed agencies responsible for recording and reporting information on abuse and neglect.

Scope of Abuse and Neglect of Individuals with Developmental Disabilities

According to my study, only four states reported having regulations regarding consent and sexual contact with adults with cognitive disabilities (Kentucky, Oregon, Washington, and Wisconsin). This is extremely troubling given the complex issues facing individuals with disabilities. The issues pertaining to sexual assault and violence against women are compounded by data presented in this report. My study also indicates vast discrepancies in definitions of assault among states and disconnect between agencies responsible for prevention, reporting, recording, and investigation.

Exposure to Multiple Providers

The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 authorized creation of the Background Check Pilot Program, directing the Secretary of the U.S. Department of Health and Human Services, "to establish a program to identify efficient, effective, and economical procedures" for conducting state and national background checks on prospective direct patient access employees (15th Annual Health Law Institute, 2008).

A major goal of the pilot was to improve on the type of screening done on direct patient access workers by requiring that a fingerprint-based state and national criminal records check be conducted, as well as a search of registries (Senate, 2010). Seven states participated in the pilot program: Alaska, Idaho, Illinois, Michigan, Nevada, New Mexico, and Wisconsin. The Centers for Medicare & Medicaid Services selected these states to represent metropolitan and rural areas, as well as diverse and ethnic populations (Senate, 2010). This program is still being developed and no national system currently exists, leaving states to conduct background checks.

Nevada provides an interesting example of service provider oversight. The State mandates that employees, who provide in-home care, work in care facilities, or residential group homes, have a fingerprint-based criminal history check through the State central repository (Nevada State Health Division, 2010). Nevada requires that all long-term care facilities use fingerprints to conduct a criminal background check on each employee and independent contractor at time of employment and at least every five years thereafter. One respondent described the reason for the original program as follows,

The Legislature was concerned for the safety of the community, meaning citizens of the State, and they enacted certain background checks, and it has grown. We have a transient population. Gaming is naturally very important to the State, so it started first with the gaming requirements to require background checks, and it has grown from there. People have said it would serve value in their industry to also have that public safety factor added of criminal background checks being performed (Nevada State Health Division, 2010).

The program in Nevada was built on the infrastructure in place to conduct background screenings of employees in various industries. Even with this developed system in Nevada the State Health Division, Bureau of Licensure and Certification is responsible for licensure and certification, but if a facility continues to employ disqualified applicants enforcement is dependent upon the State bureau's judgment (Nevada State Health Division, 2010). A lack of a national system for oversight of service providers is problematic because it directly affects how agencies report abuse.

Difficulties in Reporting Abuse

Individuals with developmental disabilities are less likely to report crimes and, when they do these individuals are often not considered convincing witnesses. Depression, self-injury, suicide, addictions, and an increase in externalized problematic behaviors are associated with the abuse of people with developmental disabilities (Ansello & O'Neill, 2010). These reactions have been observed among victims of prolonged abuse as well as single abusive events (Burke, Bedard, & Ludwig, 1998). Since people with developmental disabilities are occasionally unable to describe abusive events, the problem is worse than it seems (Sobsey & Varnhagen, 1989). Research suggests that crimes against individuals with a developmental disability often go unreported (Jenness & Sorensen, 2002; Sorensen, 1997). A 1992 study suggested that 71% of crimes against individuals with "severe mental retardation" went unreported (Wilson & Brewer, 1992). Another factor that increases the risk of abuse and neglect is the reliance of people with developmental disabilities on others for their care and support (Sobsey, 1995). These factors warrant ongoing assessment of service provisions overtime (Havercamp, Scandlin, & Roth, 2004). This type of assessment, however, would require a cohesive infrastructure for data recording.

Quantifying Abuse and Neglect

This section details the problematic aspects of accurate reporting and investigation of abuse and neglect of people with developmental disabilities among various states. The institutional policy each state uses to define and collect specifically-designed data sets will directly affect the information produced from the data. Inaccuracies, biases or compromising variables resulting from disparities between institutional policies can be mitigated with uniform operational definitions, routinely-collected statistics, pattern recognition, and large diachronic data sets.

Definitions of Neglect & Abuse

The structure of definitions is extremely important. They guide service providers in interpreting, reporting, investigating, and prosecuting abuse and neglect. With the Developmental Disabilities Assistance and Bill of Rights otherwise known as the Developmental Disabilities Act established the Protection and Advocacy system in 1975, Congress recognized that a federally directed system of legal advocacy was necessary "to ensure the humane care, treatment, habilitation and protection of persons with mental retardation, autism, cerebral palsy and other developmental disabilities" (Congress, 1995). The Developmental Disabilities Act and regulations used in implementing the act define abuse and neglect in the following way:

Abuse: any act or failure to act by an employee of a facility rendering care or treatment which was performed, or which was failed to be performed, knowingly, recklessly or intentionally and which caused, or may have caused, injury to a person with disabilities.

Neglect: a negligent act or omission by an individual responsible for providing services in a facility rendering care or treatment which caused, or may have caused, injury to an individual served or which placed an individual at risk of injury, and includes an act or omission such as the failure to carry out an appropriate individual program plan or treatment plan, failure to provide adequate nutrition, clothing or health care or the failure to provide a safe environment (Congress, 1995).

Though definitions guide reporting, confidentiality and reporting mandates plays a significant role in this issue. In the case of abuse, however, service health care agencies must understand that confidentiality is superseded by reporting mandates. Internal systems of reporting relate to reports made by service providers to local agencies or regional center. Regional agencies are mandated reporters and have an obligation to also report incidents to law-enforcement or a state agency responsible for investigations. However, many vendors believe they have met their reporting obligations when they report to the regional agencies. Furthermore, the inconsistency in definitions of reportable events confuses mandatory reporters about their obligations. These various policies and practices mislead personnel about their mandated reporting duties (Services, 2010). Any health care agency meaning any care, services, or supplies related to the health of an individual. It includes, but is not limited to, the following:

- (1) Preventive, diagnostic, rehabilitative, maintenance, or palliative care, and counseling, service, assessment, or procedure with respect to the physical or mental condition, or functional status, of an individual or that affects the structure or function of the body; and
- (2) Sale or dispensing of a drug, device, equipment, or other item in accordance with a prescription (Butts, 1967).

Though abuse is defined in both Federal and State legislation, this report indicates there is considerable variability among states' definitions and that variability makes it difficult to make valid state-to-state comparisons. Some definitions are detailed, while others are broad. Some states include only physical and emotional abuse while other definitions include abandonment as well as financial, sexual, and verbal exploitation. How a state defines abuse and neglect affect the numbers reported. As a rule, state definitions are incomplete. For example, Connecticut's definition only covers abuse by caregivers ("Report on Legislation Affecting People with Disabilities," 2010). The Connecticut Human Rights statute defines abuse as, "the willful infliction by a caregiver, of physical pain or injury or the willful deprivation of services necessary to the physical and mental health and safety" ("Report on Legislation Affecting People with Disabilities," 2010). The statute further defines caregiver as, "a person who has responsibility for the care of an individual who is a client of the department" ("Report on Legislation Affecting People with Disabilities," 2010). This definition does not say whether or not exposure to abuse from another resident constitutes the "willful deprivation of caregiver services" ("Report on Legislation Affecting People with Disabilities," 2010, p. 813). Other state definitions and statutes are written to include client-to-client abuse and harm caused by negligence. For example, Idaho's statute defines abuse as, "the intentional or negligent infliction of physical pain, injury or mental injury" ("Report on Legislation Affecting People with Disabilities," 2010). Other states have definitions that require intent and are inadequate for abuse caused by negligence. For example, in Illinois, the Abuse and Neglected Long Term Care Facility Residents Reporting Act defines abuse as, "any physical injury, sexual abuse or mental injury inflicted on a resident other than by accidental means" ("Report on Legislation Affecting People with Disabilities," 2010). Research suggests this type of definition is severely flawed and inadequate (Services, 2010). The inability to prosecute individuals for serious abuse or death caused by extreme negligence in the caretaking responsibilities necessary for working with vulnerable individuals led to revised definitions for elderly abuse and child abuse ("Abused and Neglected Child Reporting Act," 1986).

There are states with vague or narrow definitions. Others states have definitions specifically detailing abusive acts. For example, North Dakota's defines abuse as:

- Willful use of offensive, abusive, or demeaning language by a caretaker that causes mental anguish of any person with developmental disabilities;
- Knowing, reckless, or intentional acts or failures to act which cause injury or death to a developmentally disabled or mentally ill person or which placed that person at risk of injury or death;
- Rape or sexual assault of a developmentally disabled or mentally ill person;

- Corporal punishment or striking of a developmentally disabled or mentally ill person;
- Unauthorized use or the use of excessive force in the placement of bodily restraints on a developmentally disabled or mentally ill person; and
- Use of bodily or chemical restraints on a developmentally disabled or mentally ill person which is not in compliance with federal or state laws and administrative regulations. Definitional differences are related to numerical differences (North Dakota Protection & Advocacy Project, 2009).

North Dakota's law, however, is not exclusive to 'developmental disability'. In *Arizona Adult Protective Services* a state agency mandated to protect vulnerable adults from abuse and neglect. The definition for "vulnerable adult" is, "a person 18 years or older who is unable to protect him/herself from abuse, neglect or exploitation." Abuse is then defined as, "Intentional infliction of physical harm; injury caused by negligent acts or omission; unreasonable confinement; or sexual abuse or sexual assault." Arizona also has definitions for emotional abuse, neglect, and exploitation.ⁱ

The US Department of Health and Human Services define abuse as "...the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish" (Bond, 1950). The Federal definition requires a willful, purposive and assertive action as opposed to a negligent action, accidental action, or lack of action. Verbal abuse, physical abuse, sexual abuse, mental abuse, corporal punishment and involuntary seclusion are all specified in the Federal definition of abuse (Boisclair, 1998). Again, this seems severely flawed and inadequate, especially considering that funding mandates often stipulate that states to meet the federal standard (Services, 2010).

The federal definition of neglect is more consistent with most states' definitions (Parish, 2005). In federal law, "Neglect means failure to provide goods and services necessary to avoid physical harm, mental anguish, or mental illness" (Bond, 1950). According to the *Developmental Disabilities Act*, the term developmental disability means, a severe, chronic disability of an individual five years of age or older that: Is attributable to a mental or physical impairment or combination of mental and physical impairments; Is manifest before the individual attains age 22; Is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity:

- Self-care;
- Receptive and expressive language;
- Learning;
- Mobility;
- Self-direction;
- Capacity for independent living; and
- Economic self-sufficiency.

The definition goes on to state that the condition,

Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided. Without appropriate services and supports, the choices open to people with developmental disabilities including where they live, work, and play are minimal. They are isolated rather than fully integrated and included in the mainstream of society (Compilation of Selected Acts within the Jurisdiction of the Committee on Commerce Including Public Health Service Act, Developmental Disabilities Assistance and Bill of Rights Act, 1995; *Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994*, 1994).

This definition and legislation means that individuals with developmental disabilities require individually planned and coordinated services and supports (e.g., housing, employment, education, civil and human rights protection, health care) from one or more providers in order to live in the community.

Most states define *neglect* as, “a caretaker, caregiver or long-term care facility’s failure to provide food, clothing, adequate medical or personal care or maintenance that jeopardizes the life, health and safety of a vulnerable adult” (“Report on Legislation Affecting People with Disabilities,” 2010). The observable physical nature of neglect should make it easier to identify, harder to ignore. Nonetheless, state data contained in this report indicates a lack of consistency among states. This suggests problematic reporting and/or verification procedures (Congress, 2003).

Both narrowly defined and vague definitions present different issues. The way a state defines abuse has an impact on the number of abuse cases that state reports. In general, states with detailed definitions report more abuse and neglect than states with vague definitions (Services, 2010). It seems that in the absence of an explicit definition, people often do not report abuse. Therefore, a state’s relatively low abuse numbers might reflect vague definitional semantics not the absence of abuse. This is particularly problematic because federal requirements for protecting individuals with disabilities from abuse or neglect are directed at federally-funded facility providers and most individuals with a developmental disability rely on state laws and regulation for protection from abuse and neglect (Report on Legislation Affecting People with Disabilities, 2010).

In prevention of elder abuse, studies and expert committees dating back more than 15-years have recommended a uniform definition for abuse to enable more consistent data collection (Services, 2010). This data collection contributed to a framework for understanding and responding to abuse. Cohesive definitions, can improve quality and comparability of abuse data in academic research and social services; enhance systems and the ability to track trends in abuse over time; and determine the need for resources to address abuse. In the case of elder abuse, an ombudsman program was supported by federal funding from the Older Americans Act, so reporting abuse of the elderly is required nationally (Abused and Neglected Child Reporting Act, 1986; Ansello & O’Neill, 2010). A national definition, however, is not used for child abuse. Nonetheless, states and the federal government have fostered a cohesive structure to collect reliable data on child abuse, and federal reporting is legally mandated (Abused and Neglected Child Reporting Act, 1986). Experts report the data elements and definitions included in the National Child Abuse and Neglect Data System work well (Services, 2010). As this study shows, no cohesion, legal framework, or uniform definition currently exists for individuals with developmental disabilities.

A significant level of policy changes will be required to develop a national database and to communicate the qualities of data elements properly to state and local programs. A state’s participation in a voluntary national data collection effort may be more likely if the data requested are already being collected by the state.

Federal Protection Infrastructure

There are various federally funded State agencies that address developmental disabilities. The Administration on Developmental Disabilities administers programs that support State Councils on Developmental Disabilities (David L. Braddock, 2010). Members of State councils are appointed by governors and charged with identifying the most pressing needs of individuals with developmental disabilities in their state or territory. Typically State Councils on Developmental Disabilities efforts focus on systems change, capacity building, and advocacy. State Councils on Developmental Disabilities grantees also develop a state plan that lays out a state-specific blueprint for enhancing the lives of people with developmental disabilities. Then they promote public policies that are consistent with their plan, and state councils provide financial support for local activities that support their plan’s objectives (David L. Braddock, 2010). Typically State Councils on Developmental Disabilities grantees:

- Fund various training activities;
- Provide information to policymakers;
- Support the inclusion of individuals with developmental disabilities in communities; and
- Eliminate barriers to full participation in community life.

Protection and Advocacy

The Administration on Developmental Disabilities program supports a nation-wide Protection and Advocacy system (Guarding Against Abuse and Neglect: Annual Report 2000). In each state, and territory the governor designates a system to empower, protect, and advocate on behalf of persons with developmental disabilities. A Native American consortium performs the same function on Indian reservations. Once systems are designated by their governor, they are funded by Administration on Developmental Disabilities and operate independently with the authority to pursue legal, administrative, and other appropriate remedies or approaches (David L. Braddock, 2010). State Protection and Advocacy agencies work so that people with developmental disabilities have:

- Access to the legal system, appropriate education and decent housing;
- Effective and ethical guardianship, and;
- Protection from abuse and neglect.

To accomplish these goals, Protection and Advocacy funded programs provide information and referral services. They also exercise legal, administrative and other remedies to resolve problems. Protection and Advocacy activities include the investigation of suspected abuse or neglect incidents. When such a report is received, they investigate the situation to determine whether there is probable cause to believe that abuse or neglect occurred. The amount of funding received by each State's Protection and Advocacy developmental disability-funded program is based on a formula that takes into account the population, the extent of need for services for persons with developmental disabilities, as well as the financial need of the state (15th Annual Health Law Institute, 2008).

Fiscal Year	Protection and Advocacy Program Funding Awarded by Congress
2008	\$39,024,000
2007	\$37,943,640
2006	\$37,927,750
2005	\$38,108,672
2004	\$38,416,000
2003	\$36,263,000
2002	\$35,000,000

Table 1: Protection and Advocacy developmental disability program funding

In 2006, 39 States and Territories, 343 people with developmental disabilities were assisted in their efforts to obtain and maintain employment consistent with their interests, abilities, and needs. In 55 States and Territories, 6,084 complaints of abuse, neglect, discrimination of rights were remedied for individuals with developmental disabilities (Report on Legislation Affecting People with Disabilities, 2010). In 46 States and Territories, 1,531 people with developmental disabilities obtained access to affordable health care provided by qualified professionals through advice, advocacy training, legal intervention, and other forms of assistance. In 57 States and Territories, 12,242 students with developmental disabilities gained or maintained access to an array of educational opportunities in their neighborhood schools as a result of work with parents, educators, school administrators, and policy makers. In 29 States and Territories, 130 individuals with developmental disabilities gained increased accessibility to public transportation. In 49 States and Territories, 494 individuals with developmental disabilities were assisted in obtaining and retaining a residence, living where and with whom they choose (David L. Braddock, et al., 2008).

Projects of National Significance are short-term projects ("Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994," 1994). During their one to five year funding cycle these programs focused on targeted issues considered to be important to the developmental disabilities community. These are often emerging areas of concern for State Councils on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities, and other public and private entities. Generally, Projects of National Significance focus areas transcend state and territorial borders. Examples of Projects of National Significance program foci include:

- Family support, including the support of military families,
- Technical assistance to State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities programs
- Encouraging minority participation in developmental disability initiatives,
- School to the work-force transition,
- School to post-secondary education transition,
- Self-advocacy and leadership skills development,
- The creation of community-based economic opportunity, and
- Data collection and analysis (Henney, 1981).

In FY 2008, \$14.16 million was available to fund Projects of National Significance (Henney, 1981). Developmental disability agencies funded by Protection and Advocacy are required to submit annual reports of abuse or neglect and these case numbers and their annual performance reports constitute the primary abuse and neglect data source.

Each year, *Protection and Advocacy* developmental disability funded programs report the number and type of abuse or neglect cases they handle. Information from these reports is compiled and provided to the President, Congress, and the National Council on Disability. It is important to note that these reports reflect only the incidents known and considered remedied as a result of Protection and Advocacy interventions. Remedied cases only represent a fraction of reported abuse ("Annual Report of The Protection & Advocacy System 1996-1997," 1995).

In the report to congress, abuse data, neglect data, and data on discrimination cases are combined and the sum is reported. Table 2 shows the concatenated remedied case numbers reported to congress between 2002 and 2008 (15th Annual Health Law Institute, 2008).

Fiscal Year	Numbers of remedied complaints of abuse, neglect, and discrimination of rights for individuals with developmental disabilities
2008	5,241
2007	5,734
2006	6,084
2005	5,879
2004	5,917
2003	16,955
2002	16,691

Table 2: Remedied Protection and Advocacy cases

In 2008, 5,241 cases were reported to congress whereas in our study Massachusetts alone reported 6,523 cases of abuse. In fact, the total number of abuse cases for 30 states that reported a coherent number was 20,455 which stand in rather stark contrast to the 5,241 remedied cases reported by Protection and Advocacy in 2008.ⁱⁱ

Federal Agency Reports

Although individuals with developmental disabilities are not excluded from other agency reporting requirements, they are generally not a primary focus of these agencies. For example, the National Crime Victims Survey conducted each year by the Bureau of Justice Statistics categorizes and analyzes crime by victims' gender, age, racial and ethnic characteristics (Harrell & Rand, 2010). This survey, however, does not use developmental disabilities as a demographic variable. Although other agencies may include people with developmental disabilities in their statistics, their inclusion is often incidental (Harrell & Rand, 2010).

These agencies data collection activities are narrowly focused on the performance of programs and projects that they fund. For example, The Centers for Medicare and Medicaid only include people with developmental disabilities in their reporting if they are part of a Medicare waiver program or if they reside in a nursing home that is Medicare/Medicaid funded. Individuals with developmental disabilities who live in group homes, residential schools, or supervised apartments not funded by Medicare or Medicaid are unknown to those agency's data systems. As a result, any data describing abuse of neglect in places that don't receive Medicare or Medicaid funds is not indicated in agency reports (Oversight of Contract Management at the Centers for Medicare and Medicaid Services, 2010.)

The Case of Illinois

My study revealed that many disconnected agencies are tasked with the education of service providers, prevention, reporting, and investigation of abuse of individuals with developmental disabilities. The situation in Illinois exemplifies the problematic situation of various disconnected agencies responsible for these tasks (Boisclair, 1998, 1999). Illinois was looked into further because they did not respond to initial surveys and reported an inability to provide data on abuse and neglect of individuals with disabilities.

The information on abuse and neglect reporting/investigation of persons with disabilities in Illinois comes from the Department of Human Services, and states that abuse, neglect, exploitation, or death must be reported to and investigated by the Illinois Department of Human Services', Office of the Inspector General (Illinois Department of Human Services, 2004/2005). This rule is for adults receiving mental health services or developmental disabilities services. The rule in Illinois under which abuse, neglect, and exploitation are reported and assessed by the Illinois Department of Human Services' Office of the Inspector General for adults with disabilities age 18-59 in domestic living situations states,

Adult with disabilities" means a person age 18 through 59 who resides in a domestic living situation and whose physical or mental disability impairs his or her ability to seek or obtain protection from abuse, neglect or exploitation. "Domestic living situation" means a residence where the adult with disabilities lives alone or with his or her family or household members, a care giver, or others or at a board and care home or other community-based unlicensed facility, but it is not: a licensed facility....(Illinois Department of Human Services, 2004/2005)

The Department of Children and Family Services administers and provides child protective services through a State Central Register and local child protective service units.ⁱⁱⁱ It governs how child abuse and neglect is reported and how such reports are handled and investigated for all children, including those with a disability.^{iv} The Department of Human Services' Office of the Inspector General, however, **did not investigate** if the agency was licensed by another department, such as the Department of Children and Family Services and **did not investigate** once a child reached adulthood ("Laws of the State of Illinois, Ninety Sixth General Assembly, 2009: Public Act 96-001 thru Public Act 96-884," 2010).

This gap was not addressed until the 2010 legislative session with Public Act 096-1446. With this legislation Public Act 096-1446, the Mental Health and Developmental Disabilities Act, and the Department of Children and Family Services Act were changed.

The Department of Human Services' Office of the Inspector General now accepts referrals of abuse or neglect allegations of adult with a disability if they have an *Individualized Education Plan*. This means the Office of the Inspector General can only investigate under specific circumstances. The only other option is referral to law-enforcement, which does allow for reporting, and agency interventions outside current law (Abused and Neglected Child Reporting Act, 1986).

The Illinois Department of Public Health is the surveying entity for programs certified and/or licensed by the department. The Department of Public Health accepts reports of abuse and neglect from certified and/or licensed long-term care facilities and expects the facility to do a thorough and timely investigation. The Department of Public Health investigates at their own discretion (David L. Braddock, Hemp, & Rizzolo, 2008). Specific to developmental disabilities, there are both children and adults with disabilities living in Department of Public Health certified/licensed facilities (Boisclair, 1999). The Department of Public Health surveys community-based intermediate care facilities for the developmentally disabled which are licensed and must remain certified and state-operated developmental centers.^v State-operated developmental standards report allegations of abuse and neglect to both Department of Human Services' Office of the Inspector General and Department of Public Health, whereas community-based intermediate care facilities for the developmentally disabled report allegations of abuse and neglect only to Department of Public Health ("Laws of the State of Illinois, Ninety Sixth General Assembly, 2009: Public Act 96-001 thru Public Act 96-884," 2010).

The Department of Children and Family Services does not investigate abuse and neglect of adults with the exception of the new provisions in Public Act 096-1446. Although Illinois has a federally mandated Protection and Advocacy group, called *Equipment for Equality*, their booklet does not list the current mandate specified by Public Act 096-1446.^{vi}

In short, most individuals with developmental disabilities are unprotected and there are serious disconnects between the agencies responsible for the prevention, oversight, reporting, recording, and investigation of abuse and neglect of individuals with developmental disabilities in Illinois. Unfortunately, the situation in Illinois is not unique, and disconnects between agencies is not the only major problem.

National Report: Procedure and Methodology

Every state in the nation and the District of Columbia was contacted for this survey. The leaders of each state's developmental disabilities-funded Protection and Advocacy agency, and human service division for developmental disabilities services were targeted. These agencies were initially selected because –ideally– they should have access to data describing the performance of publicly funded in-state programs providing services for people with developmental disabilities. In contrast, however, state data on abuse and neglect was difficult to ascertain and often required contacting multiple agencies. Furthermore, program-specific incidents of abuse and neglect may or may not be included in these reports depending on reporting and data recording protocols.

Initially targeted programs included but not limited to those funded by:

- The Centers of Medicare and Medicaid
- The Administration for Children and Families
- The Administration for Developmental Disabilities
- Substance Abuse and Mental Health Services Administration

It was a challenge to find the contact information for each state's human service division for developmental disabilities services, and Protection and Advocacy agency. The contacts' titles included directors, assistant directors, and executive directors. In some cases, the people described in online contact information were chiefs of litigation or public information officers, not the agency's administrator. Each published contact was called and a list of accessible survey respondents was compiled. In all cases, members of the accessible sample were people who had access to and permission to release interdepartmental data describing known cases of abuse or neglect of individuals with developmental disabilities. Federally funded programs could have national reporting mandates, more cohesive definitions, and uniform reporting procedures. A letter and a survey instrument were developed by project staff. The letter referred to the previous telephone contact, described the survey, and asked recipients to carefully respond to the survey. The survey required respondents to enter a ten-year history of the number of reported cases of abuse and neglect of individuals with developmental disabilities in their state.

In January of 2009 letters and a survey instrument were mailed to members of the accessible survey sample. The letter was followed by an e-mail with an attached copy of the letter and survey instrument. Four months after the first mailing, a second mailing was sent to members of the sample who had not responded.

Representatives of the following States responded to the survey: Alabama, Alaska, Arizona, Arkansas, California, Connecticut, Delaware, District of Columbia, Florida, Georgia, Idaho, Indiana, Iowa, Kentucky, Louisiana, Maryland, Massachusetts, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Utah, Vermont, Washington, West Virginia, Wisconsin, plus two states that provided information on abuse and neglect but did not include any identifier as to who they were.

Illinois and South Dakota responded after repeated attempts to various agencies. As previously stated, the response from Illinois did not contain recorded numbers. Information on the state of affairs in Illinois is stated early in this report. The following states did not respond to the survey: Colorado, Hawaii, Kansas, Maine, Michigan, Minnesota, Mississippi, New Mexico, Texas, Virginia, and Wyoming.

Preliminary Findings

Preliminary data suggested that Protection and Advocacy Agencies were required to submit an annual report to the Department of Health and Human Services on the number and type of abuse or neglect incidents they handled. These annual performance reports from individual Protection and Advocacy Agencies agency constitute the primary source of information for the Department of Health and Human Services on abuse or neglect of people with disabilities (Protection and Advocacy Agencies Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities, 2003). The submitted information is compiled and reported to the President, Congress and the National Council on Disability. These reports include only the incidents that were reported to Protection and Advocacy agencies. As a result, the Department of Health and Human Services receives very limited information on incidents of abuse and neglect which makes it difficult to identify the numbers of the incidents as well as the possible systemic problems that exist. State agencies are not required to report to the Department of Health and Human Services any information on incidents of abuse and neglect of people with disabilities. Of the states that provided data:

- Only seven were from *Protection and Advocacy* agencies;
- Twenty-eight were from *Developmental Disability Divisions*;
- Six states responded that either they did not gather data or they are unable to provide data because it is not available;
- Only five states provided data for the ten years requested;
- Five states provided numbers of abuse and neglect combined into one category;
- Three states reported separate numbers of reported and substantiated abuse and neglect incidents;
- Definition of abuse and neglect differs by state with some states including subcategories such as physical, sexual, financial verbal, exploitation, self-neglect, physical assault, human rights violations, etc., and;
- Data was provided from two states with no identification.

Only 38 states and the District of Columbia responded to the survey. Of these 38 states only 22 listed agencies responsible for gathering data on abuse and neglect. Of the 22 states with identified agencies, 9 listed multiple agencies responsible for recording data.

Table-3 is a list of state agencies responsible for collecting abuse and neglect of individuals with developmental disabilities.

Table-3: State Data Collection Agencies

State	Agency
Arizona	Department of Economic Security Division of Developmental Disabilities
Delaware	Division of Developmental Disabilities Services
Georgia	Georgia Department of Human Resources Division of Mental Health, Developmental Disabilities, & Addictive Disorders
Idaho	Idaho Department of Health & Welfare, Division of Medicaid
Indiana	Indiana Family & Social Services Administration, Division of Disability, Aging, & Rehabilitative Services
Iowa	Iowa Department of Human Services
Kentucky	Kentucky Cabinet for Families and Children Adult Protective Services
Maryland	Developmental Disabilities Administration Department of Health and Mental Hygiene
Massachusetts	Disables individuals Protection Commission
Missouri	Department of Mental Health Division of Mental Retardation and Developmental Disabilities
Montana	Adult Protective Services
Nebraska	Nebraska Health and Human Services System-Adult Protective Services
Nevada	Department of Human Resources Division and Mental Health Services
Oklahoma	Department of Human Services Developmental Disabilities Division
Oregon	Department of Human Services Office of Investigations and Training, Health Services
Pennsylvania	Department of Public Welfare Office of Mental Retardation
South Carolina	Department of Social Services
Tennessee	Tennessee Department of Human Services Adult Protective Services Tennessee Department of Finance and Administration Division of Developmental Disabilities Tennessee Department of Mental Health and Developmental Disabilities
Utah	Utah Adult Protective Services
Vermont	Department of Aging and Disabilities Division of Licensing and Protection Vermont Adult Protective Services
Washington State	Department of Social and Health Services Adult Protective Services
Wisconsin	Wisconsin Department of Health and Family Services

Findings

This section highlights some of the key finding of our report. According to the information obtained for this report, only:

- Four states reported regulations regarding consent and sexual contact with adults with cognitive disabilities (Kentucky, Oregon, Washington, and Wisconsin);

- Two states reported an accreditation requirement for providers of services to adults with developmental disabilities (Missouri and Ohio);
- Fourteen states indicated mandated reporting for abuse and neglect of individuals with developmental disabilities;
- Ten states have human rights training for staff, and;
- Eleven states reported prevention training for staff working for individuals with disabilities.

According to anecdotal accounts and preliminary research victim service agencies are often inaccessible and do not provide appropriate support and services for people with disabilities. Recommendations focus on cross-system collaboration to provide access to victim services by all victims, including those with disabilities.

Given the high rates of abuse and the likelihood that perpetrators are family members, personal assistants, or support staff, it seems essential that women with disabilities have access to victim services such as rape crisis centers and domestic violence programs, including counseling, legal services, and emergency and transitional housing (Frantz, Carey, & Bryen, 2006).

Among the greatest barriers to accessibility are limitations in staff awareness of the broader issues of accessibility and disabilities, negative or ambivalent attitudes about providing greater access, lack of knowledge of the prevalence and incidence of sexual victimization within the disability community, and limited recognition of the sexuality of people with disabilities.

Inaccessible transportation affects the ability of persons with disabilities to travel freely, thereby limiting their full utilization of victim service programs (Frantz et al., 2006).

Individuals with developmental disabilities are less likely to report crimes and, when they do these individuals are often not considered convincing witnesses. Another factor that increases the risk of abuse and neglect is the reliance of people with developmental disabilities on others for their care and support. As a result, abusive events may be unreported and undocumented ("Report on Legislation Affecting People with Disabilities," 2010).

Though definitions guide reporting, confidentiality and reporting mandates plays a significant role in this issue. In the case of abuse, however, service health care agencies must understand that confidentiality is superseded by reporting mandates. Internal systems of reporting relate to reports made by service providers to local agencies or regional center. Regional agencies are mandated reporters and have an obligation to also report incidents to law-enforcement or a state agency responsible for investigations. However, many vendors believe they have met their reporting obligations when they report to the regional agencies. Furthermore, the inconsistency in definitions of reportable events confuses mandatory reporters about their obligations. These various policies and practices mislead personnel about their mandated reporting duties.

Though abuse is defined in both Federal and State legislation, this report indicates there is considerable variability among states definitions and that variability makes it difficult to make valid state-to-state comparisons. Some definitions are detailed, while others are broad. Some states include only physical and emotional abuse while other definitions include abandonment as well as financial, sexual, and verbal exploitation. Obviously, how a state defines abuse and neglect affect the numbers reported. Both overly narrow or vague definitions and overly defined or inclusive definitions present different issues. The way a state defines abuse has an impact on the number of abuse cases that state reports. In general, states with detailed definitions report more abuse and neglect than states with broad definitions. It seems that in the absence of an explicit definition, people do not choose to report abuse. Therefore, a State's relatively low abuse numbers might reflect vague definitional semantics not the absence of abuse. This is particularly problematic because federal requirements for protecting individuals with disabilities from abuse or neglect are directed at federally-funded facility providers and most people with developmental disabilities rely on state laws and regulation for protection from abuse and neglect.

Definitions of neglect are generally less obscure and varied than definitions of abuse. The observable physical nature of neglect should make it easier to identify, harder to ignore, and more likely to be reported. Nonetheless, the state data contained in this report indicates a lack of consistency among states. This suggests problematic reporting and/or verification procedures.

A significant level of policy changes will be required to develop a national database and to communicate the qualities of those data elements properly to state and local programs. A state's participation in a voluntary national data collection effort may be more likely if the data requested are already being collected by the state.

Each year, Protection and Advocacy developmental disability funded programs report the number and type of abuse or neglect cases they handle (Report on Legislation Affecting People with Disabilities, 2010). Information from these reports is compiled and provided to the President, Congress, and the National Council on Disability. It is important to note that these reports reflect only the incidents known and considered remedied as a result of Protection and Advocacy interventions. Remedied cases only represent a fraction of reported abuse as evidenced in through this study.

The Centers for Medicare and Medicaid only include people with developmental disabilities in their reporting if they are part of a Medicare waiver program or reside in a nursing home that is Medicare/Medicaid funded. Individuals with developmental disabilities who live in group homes, residential schools, or supervised apartments that are not funded by Medicare or Medicaid are unknown to those agency's data systems. As a result, any data describing abuse or neglect in places that don't receive Medicare or Medicaid funds probably will now show up in agency reports (Senate, 2010).

From the data collected in this study, we conclude, that the current system is inadequate for individuals with developmental disabilities for the following reasons. First,

- It vastly obscures and underrepresents abuse, neglect, and victimization in this population;
- Second, It provides unreliable, inconsistent data concerning the range and scope of the problem, and;
- Third, There is no central reporting system or national registry that compiles data useful to inform policy and practices and adequately protect the human rights of individuals with developmental disabilities.

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Notes

ⁱ Arizona Protective Services Statute: A.R.S. " 46-451 to 457. Statute regarding disclosure of confidential information: A.R.S. ' 41-1959; Special Visitation Warrants for APS workers: A.R.S. ' 14-5310.01; Criminal statute for abuse of vulnerable adult or child: A.R.S. ' 13-3623. Accessed 2/3/2001 at: <http://www.acdl.com/pdfs/DDD1NewAddress.pdf>

ⁱⁱ Note: two states did not report any data for 2008, and six states record data in a manner that cannot be disaggregated annually.

ⁱⁱⁱ Department of Children and Family Services (Department of Children and Family Services) Part 300 located online at: <http://www.state.il.us/dcf/docs/300.pdf>

^{iv} 20 ILCS 515/107

^v These are not licensed but must remain certified for Medicaid funding under both state and federal (ICFMR) standards. See (Hemp, Braddock, & King, 2006; *Oversight of Contract Management at the Centers for Medicare and Medicaid Services: Hearing before the Ad Hoc Subcommittee on Contracting Oversight of the Committee on Homeland Security and Governmental Affairs, United States Senate, One Hundred Eleventh Congress, Second Session, April 28, 2010, 2010*)

^{vi} See http://www.equipforequality.org/publications/aiu_handbook.pdf