CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

Reducing Incidents of Abuse, Neglect and Wrongful Death among Californians with Developmental Disabilities

A graduate project submitted in partial fulfillment of the requirements

For the degree of Master of Public Administration in Public Sector Management and Leadership

By

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Table of Contents

Abstract

Improving Abuse, Neglect and Wrongful Death prevention for Californians with Developmental Disabilities

By

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Master of Public Administration in Public Sector Management and Leadership

This research will seek to determine if California's multi-agency and Regional Center system is effective at reducing allegations of abuse, neglect and wrongful deaths among individuals with developmental disabilities. The research will be conducted using a quantitative causal research design in which a survey questionnaire will be sent to a random sample of 1,000 California Regional Center and Developmental Center employees. The study expects to find that improvements can be made in the administration of developmental disability programs statewide particularly if the Department of Developmental Services had an increased ability to implement policy over the Regional Centers.

Introduction

California has over 356,000 individuals with Development Disabilities (DD), including intellectual disability, cerebral palsy, epilepsy, autism and related conditions (California Department of Developmental Disabilities, 2019). The term developmental disability refers to a "severe and chronic disability that is attributable to a mental or physical impairment that begins before an individual reaches adulthood" (California Department of Developmental Disabilities, 2019). These individuals are the some of the most vulnerable in the state to become victims of abuse, neglect and occur wrongful deaths (Disability Rights California, 2019). For example, because of their disability, individuals with DD are victims of nearly one million more nonfatal, violent crimes every year than those without developmental disabilities (Harrell, 2014).

In California State Developmental Centers (DC's) alone since 2002, there were 13 wrongful deaths caused by abuse and neglect (Bale, 2015). These deaths included a slow death from a misplaced feeding tube that went unnoticed, a client to client murder due to neglectful staffing rounds, and a death from a MSRA infection that went unnoticed and untreated despite appearing on the individual's lab results (Bale, 2015).

The DD population is the most susceptible to suffer abuse, neglect and wrongful deaths for a variety of reasons. These reasons include a perception that DD individuals are easy targets, they live in segregated environments where abuse is more easily hidden, they have limited communication skills to report abuse, and they are often dependent on a select few caregivers to survive, caregivers who can also be abusive (Abuse and Exploitation of People with Developmental Disabilities, 2019). With DD individuals being particularly vulnerable to abuse, neglect and wrongful death, and also potentially having difficulty reporting such abuses, it is

worthwhile to examine whether the public administration system in California is designed in such a way as to prevent and reduce abuse, neglect and wrongful deaths from occurring. Public data on these incident types is not easy to find, and in fact can only be obtained by the public via a Public Records Act (PRA) request to the Department of Developmental Services (DDS), such as one that was recently done by 538.com in a 2018 article (Calma, 2018). While the data does not show any alarming trends as far as a rapid increase in allegations in recent years, there are thousands of incidents that fit into the abuse, neglect and wrongful death category each year (Calma, 2018). Although the numbers can be shocking and upsetting at face value, they can be almost meaningless without a better understanding of the way the developmental disability system works in California, and which agencies and entities become involved when such an incident occurs.

The system of identifying and following up with an abuse allegation is an effective one in theory. The home or work services vendor is required by law to report any allegations of abuse, neglect or death to the Regional Center (RC) of the DD individual within 48 hours, and the RC insures that the proper licensing entities as notified, as well as DDS (CA Code of Regulations Title 17, 2019). Because each individual with DD receives services and supports from so many different vendors, whose programs are overseen by multiple entities, it can be difficult for the DD system as a whole to keep track of emerging trends and existing patterns. For example, certain work services or home vendors might mostly operate in Kern County, which would mean Kern Regional Center (KRC) would know much of the relevant information available to make decisions regarding approval of that vendor to continue operations. However, if some of these work services or home vendors had a small number of abuse allegations in KRC's jurisdiction but a high number state-wide, then KRC would be reliant on data sharing with all 20 other RCs

to make effective licensing decisions. Unfortunately, due to a landmark court decision in 1985 called *Association for Retarded Citizens v. Department of Developmental Services*, DDS has no power to enforce or mandate the RC's to spend money on specific programs based on the structure of their contracts (Van Riper, 1985). Thus, it has no power to force the RC's to share data on vendors with a history of high abuse rates.

Vendors serving multiple RC's are not the only issue. In a large state such as California, it might be possible for an employee with a record of suspected abuse to get fired by one vendor and get a job in the future at another vendor under a different RC, as there is typically a high demand for employees such as Psychiatric Technicians (PT's) in that line of work. Once again, DDS does not have the capability of tracking all individuals working for developmental disability vendors, nor the enforcement power to ensure that all 21 RC's are sharing that type of data effectively (California's Developmental Disability System, 2013). The only thing preventing an employee with a track record of abuse getting hired by another vendor served by a new RC is the annual license renewal for employees such as PT's. However, it is not the RC's or DDS that has license renewal power, it is the Board of Vocational Nursing and Psychiatric Technicians (BVNPT) (California S. of., n.d.). Theoretically the license renewal process is effective, but there is no single entity that allows California a way to track this, as DDS has no power over the BVNPT (California S. of., n.d.). The current developmental disability system in California is designed to be adept at providing local services based on an individual's RC, but it might be at the cost of easier recognition of abuse trends and troublesome vendors statewide.

With three separate state agencies, DDS, DSS, DPH, and 21 private RC's providing services, licenses, and interacting with Californians with DD, quality assurance and risk management is not an easy endeavor. There are policies and procedures in place for every

possible scenario when it comes to dealing with allegations of abuse, neglect and wrongful death (CA Code of Regulations Title 17, 2019). However, with so many moving parts and entities involved, it is difficult to tell if California is effective in reducing such occurrences.

The DD population in California is expected to continue to increase, particularly with the rapidly expanding rates of Autism diagnosis (California Department of Developmental Services, 2019). With such a large population that has been proven to be more vulnerable to be a victim of crime than the population at large, it is worth examining the existing DD system in California. This is particularly true because with so many public and private entities comprising the DD system, it might be especially difficult to substantiate allegations of individual caregivers or vendors committing abuse and neglect and permanently ban them from providing services. The complicated public administration system of DD services and supports in California raises questions. Most importantly, would an increase in DDS authority over the RC system help to reduce allegations of abuse, neglect and wrongful deaths among Californians with developmental disabilities?

Background

DDS provides services and supports to hundreds of thousands of Californians with Developmental Disabilities. But for a variety of reasons, it is not a one-stop shop for providing these services, nor for enforcing its policies. Instead of having a massive state department that directly oversees all services that a Californian with DD receives, California contracts with 21 non-profit private corporations called RC's spread throughout California (California Department of Developmental Services, 2019). The system of DDS contracting with the 21 RC's was established with the passing of the Lanterman Act in 1969, with the intention that the RC's would "be accessible to every family in need of regional center services" (California Welfare and Institutions Code 4620, n.d.). The role in which government has played in developmental disabilities services continues to evolve. In the early 1970's changes to Medicare allowed the federal government to shift its longstanding practice of "warehousing" individuals in large institutional facilities and begin transitioning these individuals into community-based settings (Agranoff, 2013, p.4). The movement to provide increased services and supports continued with the passage of the Americans With Disabilities Act (ADA) in 1990. The legislation mandated that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (Wood, 1998, p.503). With a continued focus on integration, "I/DD has moved outward from government in some ways, but in others it remains highly governmental. Externalization of services has not necessarily displaced or totally eliminated public agencies, it has changed them" (Agranoff, 2013, p.11).

The Lanterman Act remains in effect in California, and thus the RC's are the entity that the public interacts with, not DDS. With the exception of several hundred individuals that

remain in DDS state-operated facilities, the 356,000 individuals with DD typically live at home with family and are eligible to receive RC services (California Department of Developmental Services, 2019). Those that do not live with family live in group homes across California that are operated by private vendors who have been approved by their respective RC to provide services and be reimbursed accordingly via Medicaid funding (California Department of Developmental Services, 2019).

As the designated organization for DD services in their respective areas, each RC helps to coordinate a wide-range of services for each one of their clients. The services include day programs, education, work, supported living, in-home, and transportation (California Department of Developmental Services, 2019). In this regard, the only difference between an individual with DD and one without such a disability in California is that the services and vendors used by the DD individual need to be approved by their RC.

In addition to the required RC approval of vendors providing DD services, there is a separate licensure process for the homes that DD individuals reside in. For example, Community Care Facilities (CCF) provide 24-hour non-medical residential care for individuals with DD and are licensed by the Department of Social Services (DSS), not DDS (California Department of Developmental Services, 2019). Another home type, Intermediate Care Facilities (ICF) are licensed by the Department of Public Health (DPH), once again not DDS (California Department of Developmental Services, 2019). Thus, in many cases removing a license from a vendor with a high rate of abuse might fall under the jurisdiction of DSS or PDH, but they do not have access to all available RC data on incidents of abuse, neglect and wrongful death.

Literature Review

The purpose of this literature review is to address the academic research that has been conducted in the last 20 years around the abuse, neglect and wrongful death of individuals with DD. The first section of the literature review will focus on abuse against vulnerable populations in general. The second section will focus on the theoretical framework of abuse, neglect and wrongful death among the DD population while the third section will focus specifically on mortality among DC movers in California. The final section will cover previous research among incidents and abuse prevention methods for the DD population as a whole.

Abuse against Vulnerable Populations

While discussing the prevalence of abuse and neglect against the developmentally disabled population, it is relevant to review how vulnerable other groups might be to similar maltreatment. Callard, Felicity, Sartorius, Norman, Arboleda-Flórez, Julio, Bartlett, Peter, Helmchen, Hanfried, Stuart, Heather, Thornicroft, & Graham. (2012) mention that "people with intellectual disabilities, children, the elderly, people with mental illness and prisoners are traditionally considered vulnerable" (p.141). Among individuals without DD, children and elderly populations have been examined at length for their vulnerability to abuse. Acierno, Hernandez, Amstadter, Resnick, Steve, Muzzy, & Kilpatrick, (2010) studied abuse and neglect of adults who were over 60 with a random national sample of 5777 respondents (p.292). Acierno, et al., found that "one in 10 respondents reported emotional, physical, or sexual mistreatment or potential neglect in the past year" (p.292). They concluded that the elderly abuse is prevalent (Acierno, et al., 2010).

Finkelhor, Jones, & Shattuck (2010) studied data on substantiated child maltreatment from the National Child Abuse and Neglect Data System (NCANDS) that was released in 2010 (p.1). Finkelhor et al., (2010) noted that the data revealed that the substantiated child maltreatment rate was actually declining, at a rate of 3% annually (p.1). They further mentioned that the 2010 rate was the "lowest level of child maltreatment since the NCANDS system was put into place in 1990" (Finkelhor et al., 2010, p.1). Unfortunately for the DD population, there is not a NCANDS equivalent, which makes data collection and the study of abuse, neglect and wrongful death incidents much more difficult.

Abuse, Neglect and Wrongful Death Reporting Challenges

In California, allegations of abuse, neglect and wrongful death are reported by vendors to the RC in which the incident took place. These notifications are then passed on to DDS and additionally DPH or DSS depending on the license type of the vendor caring for the individual for which such an incident was reported (California Code of Regulations, Title 17, 2019). It is important to note that the reporting requirements of Title 17 are clearly spelled out in order to protect Californians with developmental disabilities because according to Hughes, Bellis, Jones, Wood, Bates, Eckley & Officer (2012), "adults with disabilities are at a higher risk of violence than are non-disabled adults" (p. 1621). This assertion is supported by Horner-Johnson, Drum, Frey, Georgia,Temple, Viviene & Stanish, Heidi (2006) who studied all prior research on this topic for a ten-year period from 1995-2005. The study conducted by Horner-Johnson et al., (2006) suggested that abuse neglect and wrongful death was more prevalent for people with DD than for people with no disabilities and might be higher for people with DD than for people with disabilities in general (p.58). They did include a caveat that the limited amount of data was a

high hurdle to clear in order to address the abuse of people with DD (Horner-Johnson et al., 2006, p.58).

According to Calma (2018) data on the number of abuse and neglect allegations made each year is not publicly provided by DDS, but information can be requested through a PRA. For example, Calma (2018) submitted a PRA in 2018 and learned that adult day programs in California self-reported 1,964 incidents of suspected abuse from January 2013 to December 2017. In the same period, there were 463 allegations of neglect (Calma, 2018).

One of the most challenging things about studying allegations of abuse and neglect amongst the developmentally disabled population is investigating and substantiating those allegations. According to McCormack, Kavanagh, Caffrey, & Power, (2005) "investigating sexual abuse where people with intellectual disabilities are alleged victims or perpetrators raises additional difficulties because of their limited comprehension, their suggestibility, their lack of understanding of abuse and, in some instances, their inability to give consent" (p.218).

Mandell, Walrath, Manteuffel, Sgro, and Pinto-Martin (2005) studied abuse in a sample of 156 autistic children from 1997-2000 and found that 18.5% of children with autism had been physically abused and 16.6% of children with autism had been sexually abused (p.1359). Mandell et al., noted that these rates indicated a "high prevalence of sexual abuse among children with autism" (p.1369).

McCormack et al., (2005) reported on a 15-year review of documented cases of sexual abuse of persons with developmental disabilities receiving services from a large area and group of community-based agencies in Ireland. Their study noted primarily male perpetrators but an "equal number of male and female victims, with 65% of cases involving touching and

masturbation and 31% involving attempted or actual penetration" (McCormack et, al., 2005, p.222). Over the review period, McCormack et al., (2005) found that although there was a high rate of sexual abuse assaults that had been committed by the peers of the victims, there was also an unambiguous increase in sexual abuse perpetrated by staff, especially in multiple instances of abuse (p.222). Research conducted by Bowman, Scotti, & Morris (2010) also showed that "the largest group of identified perpetrators of sexual abuse is developmental disability service providers" (p.119).

It is unsurprising that service providers are commonly identified as perpetrators because of the way in which the developmental disability population is vulnerable to being abused. Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2015) found that people with DD often "lack the skills to make effective, self-protective decisions" (p.490). Eastgate, G., Scheermeyer, E., Van Driel, M., & Lennox, N. (2012) describe how individuals with DD have difficulty communicating with others that they were abused, whether it be because they are not assertive enough to do so or simply lacking in communication abilities (p.135). Eastgate et al., (2012) note that simply reporting abuse is not enough, as the responses to the abuse are often lacking because the burden of proof to substantiate abuse is difficult to achieve when the victims cannot clearly articulate the manner in which they were abused (p.135).

In addition to investigating and substantiating abuse, it has been difficult in the past to gather accurate statistics surrounding wrongful death in the developmental disability population. Mortality among the adult developmental disabled population in Ontario was studied from 2011-2014 by Stankiewicz, E., Ouellette-Kuntz, H., McIsaac, M., Shooshtari, S., & Balogh, R. (2018) who noted that "despite apparent decreases in mortality among adults with IDD, excess mortality remains" (p.871). Stankiewicz et al., acknowledged that many of the causes of death for

individuals with DD are unknown, and thus it was extremely challenging to pinpoint why individuals in the population studied were dying more frequently than would otherwise be expected (p.871). To combat this, they suggested that more "care should be taken with cause of death reporting so that reasons for these disparities can be further explored" (Stankiewicz et al., p.871). Furthermore, they mentioned that additional research needed to be conducted to better understand how certain deaths could be avoided by better healthcare practices and services or other means among the DD population. (Stankiewicz et al., 2018, p.871)

Additional research on mortality among the developmentally disabled population was conducted by Landes, Stevens, & Turk (2019), who reviewed a study population of 33,154 adults with a developmental disability indicated on their birth certificate who died between 2012 and 2016 (p.1). According to Landes, et al., (2019), there is increasing consensus that "developmental disabilities should not be considered a valid underlying cause of death (UCOD), as doing so prohibits identification of the preventable medical cause of death and is not advantageous to public health or preventive care efforts" (p.2). Landes et al., suggest that the problem is the way in which physicians are currently instructed to code death, as they are currently using developmental disability as a catch all for UCOD, when that's not actually the reason an individual passed away (p.2). They state that choosing a UCOD that is more accurate than DD will be of large help to public health and preventative care efforts to lower the amount of wrongful deaths amongst individuals with DD (Landes, et al., 2019, p. 9).

Incidents Among Developmental Center Movers

The living environments for the vast majority of Californians are not state-run institutions as they were prior to the Lanterman Act. Instead, Agranoff (2013), reports that in California

today there are a wide range of DD programs for individuals with differing types of disabilities in community homes and day programs which have mostly replaced public institutions such as the DC's (p.1).

The process of moving the individuals that lived in the DC's into community settings has been a gradual one, which has allowed time for studies to be conducted on the welfare of those individuals who moved from DC's to small community home settings. According to Strauss, Shavelle, Baumeister and Anderson (1998), more than 2,000 persons with developmental disability transferred from California institutions into community care during 1993 to early 1996 (p.855). Using data on 1,878 children and adults who moved between April 1, 1993 and March 5, 1996, Strauss, et al. (1998) found a corresponding increase in mortality rates by comparison with those who stayed behind (p.857). Strauss, Cable & Shavelle (1999) updated the study through 1996 and found similar results. They reported "81 deaths, a 47% increase in risk-adjusted mortality over that expected in institutions" (p.582). Over the course of all three studies, Shavelle, R., Strauss, D., & Day, S. (2005) "found that the DC mover population who moved later were at greater risk of mortality than those that transferred earlier, including the factoring in of mortality risk factors for the population (p.371). They discovered that the community model has provided less intensive medical care and supervision than the DC's, exposing the mover population during that time to an increased mortality rate (Shavelle, et al., 2005, p.371). Ultimately the study by Shavelle et al., (2005) of the DC movers in the mid 1990's concluded that "the results in this and previous studies indicate an increased mortality rate, above that which would be expected" (p. 378).

Previous Research

Preventing abuse neglect and wrongful death among individuals with developmental disabilities is not a unique problem to California, and in fact there has been some atrocities committed in this area globally. For instance, Bayat (2015) reported that in West Africa in particular Cote d'Ivoire and Ghana, there are ritual killings or abandonment of what they call snake/spirit children, who are actually children with developmental disabilities. These "snake children" killings could be as high as 22-27% of all infant mortalities of unexplained causes in Ghana (Bayat, 2015).

The United States and California do not have the same problems as West Africa with ritualistic sacrifice of children with developmental disabilities, but according to (Lund & Hammond, 2014) "abuse and violence against people with disabilities is a well-documented problem" (p.99). Despite this Lund and Hammond (2014) lament that "the scholarly literature contains relatively few disability-specific abuse prevention programs (p.99). The lack of such programs particularly in rural areas inspired Lund & Hammond, (2014) to advocate The Stopping Abuse for Everyone (SAFE) curriculum as a single-session abuse psychoeducation program for individuals with DD (p.99). Lund & Hammond designed their program to be delivered in rural areas of the United States to individuals with DD who are not typically able to attend abuse prevention training of any kind (p.99).

McCormack, et al., (2005) note the crucial role of early detection in abuse prevention, because it stops ongoing abuse, and even the potential for other victims to fall victim to the abuser (p.226). Unfortunately, some of the patterns of abuse among those with developmental disabilities can be cyclical as Lindsay, Septoe and Haut (2012) confirmed in their research in the

United Kingdom. They studied 477 individuals with developmental disabilities that were in the penal system as abuse offenders and found that while males who had suffered child abuse could be on a pathway to becoming abusers themselves, females were most vulnerable to all forms of abuse (Lindsey, et al., 2012, p.326).

Another possibility for reducing abuse is the ESCAPE-DD curriculum which was reported to be effective by Khemka, Hickson & Reynolds (2005). ESCAPE (An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment) is a curriculum based on Khemka's (2000) cognitive/motivational intervention that also addressed emotional aspects of decision making. (p.491). A further study by Hickson, Khemka, Golden & Chatzistyli (2015) used a sample of 71 men and women with mild to moderate IDD from seven adult day programs in New York city with no prior training with ESCAPE-DD (p.492). The research of Hickson et al., (2015) indicated that "participation in the ESCAPE-DD curriculum intervention was associated with increased application of effective decision-making skills in response to scenarios involving sexual, physical, and verbal abuse (p.500). Hickson et al., (2015) also noted that those who received ESCAPE-DD training had significantly improved scores in their effective and safe decision-making skills as compared to those who had not received training (p.500).

Mahoney & Poling (2011) studied past research in the abuse prevention field such as the work done by Khemka et al., (2005). They suggested that organizations should consider incorporating an abuse-prevention model into their management system (p.374). Mahoney & Poling (2011) supposed that "such a model ought to include manager oversight of direct care staff, staff training on signs and symptoms of abuse, and administration training on the steps to take when abuse is reported" (p.374). Thus, they stated that a comprehensive intervention would involve training staff on abuse precursors, prevention, reporting and recognition, client training

on avoiding and reporting abuse, and the training of all management staff who would be responsible for the program implementation of annual abuse training (Mahoney & Poling, 2011, p.374).

Knowledge Gaps

In the process of the literature review gaps were identified in the research. The vast majority of the studies only examined a subset of the population, such as the one conducted by Strauss et al., (1998) in their study of the California DC movers, or the research done by McCormack et al., (2005) on sexual abuse in the United Kingdom. The history and complexity of California's developmental disability system has been extensively chronicled by experts such as Agranoff (2013), but there has been little to no examination of what is being done to reduce incidents of abuse neglect and wrongful death, mostly because the information is not publicly available, as noted by Calma (2018). The fact that services and supports are provided by 21 different RC's that DDS only has partial oversight over adds an additional layer of difficulty in trying to parse out how California is doing as a state in its efforts to reduce such incidents (California Department of Developmental Services, 2019). While the research conducted by Woods et al., (2012) has made it clear that such incidents are inevitable due to the nature of the population involved, there is little reason to believe that California's public administration of the developmental disabilities field cannot improve in its efforts to prevent harm to this most vulnerable population. This study will attempt to address the disparity in the research by examining the process in which the RC's, DSS and DDS implement quality assurance and risk management to reduce allegations of abuse, neglect and wrongful death statewide.

Methodology

This project will examine incidents of abuse, neglect and wrongful death among Californians with developmental disability (DD), and the success or lack thereof in California's developmental disability organizations such as the 21 Regional Centers (RC's) and the Department of Developmental Services (DDS) at reducing such incidents. A quantitative research method will be used, in addition to a Public Records Act (PRA) request to DDS. This project aims to answer the following hypotheses:

1. An increase in DDS authority over the 21 RC's will reduce the amount of abuse, allegations
2. An increase in DDS authority over the 21 RC's will reduce the amount of neglect allegations.
3. An increase in DDS authority over the 21 RC's will reduce the amount of wrongful death.

Research Design

This project has a causal comparative research design. There will be a survey questionnaire with closed-ended questions using a five-point Likert scale. A causal comparative research design was chosen because it aims to explore the relationship between the independent and dependent variables (Samii, 2016). For the purposes of this project, the independent variables are increased DDS oversight of the RC's, and a uniform mandated abuse prevention training. The research aims to test if the implementation of those variables would have an impact on reducing the dependent variables, which are incidents of abuse, neglect and wrongful death among the DD population in California. Each question will include a possibility of

responses that range from “strongly agree to strongly disagree”. Central tendency statistics (mean, median and mode) will be calculated and collected.

Settings and Participants

There are 21 RC’s distributed throughout California, with centers concentrated more heavily towards the largest population centers such as Los Angeles county, which includes 6 RC’s (California Department of Developmental Services, 2019). The largest regional centers by population size are Alta California (ACRC) and Central Valley (CVRC) with 25,000 and 21,000 individuals respectively (California Department of Developmental Services, 2019). Valley Mountain (VMRC) at 9,000 individuals is the smallest (California Department of Developmental Services, 2019). In addition, there are currently two developmental centers (PDC and FDC) and one community facility (CS) run by the state that remain open, as well as the department headquarters in Sacramento (California Department of Developmental Services, 2019). Because DDS contracts with the RC’s, and the DC’s provide direct services, it is vital to include them among the survey participants. With the permission of DDS and the 21 RC’s who they contract with, a sampling frame of all staff will be provided. The sampling frame will be used to pull a simple random sampling of all employees from the RC’s, DC’s, and DDS HQ. This will be done to survey the perspective of employees that work with DD programs in California in different ways. The study anticipates a potential maximum sample of 500 respondents. Conducting the survey in this manner will allow for an equal distribution of staff to be surveyed statewide, instead of stratified sampling by employee groups, which would likely cause employees from smaller RC’s to be overly represented.

A survey will be distributed to collect data for the project. The survey will be consisted of 25 close-ended questions and divided into 3 sections. The first section includes background questions about job title, job experience and gender. The second section is designed to determine the respondent's degree of familiarity with abuse, neglect and wrongful death among DD individuals in California. The third section will measure the level of the respondent's interest in and ability to change the status quo of the DD system. Examples from all three sections of the survey are as follows:

1. I have previously undergone DD abuse prevention training with my current employer.
2. I am familiar with abuse, neglect and wrongful death incidents among the DD population in California.
3. I believe that increased DDS oversight of the RC's would reduce abuse, neglect and wrongful death.

In addition to my survey questionnaire, a PRA will be given to DDS. The purpose of the PRA will be to gather statistics on the past ten years of abuse, neglect and wrongful death incidents that occurred both in the community and at the DC's. The request will also include the number of individuals served each year per RC and DC, as the rising DD population in California makes it necessary to compare an annual incident rate, and not simply compare total incident counts. Furthermore, the PRA will include identifiers for the RC, vendor type, sex, age, disability level and diagnosis of the individual involved in each incident. From this data, statistical analysis using a P-Score will be used to determine if there has been any significant increase or decrease in abuse, neglect or wrongful death across California. In addition, data from each individual RC and DC will be examined to see if there are areas the state should be concerned about even if the overall incident rate is trending downward.

Ethical Considerations

Eligible participants will be recruited exclusively from the adult staff of the RC's, DC's and DDS HQ. The project has obtained permission to distribute this survey to each RC, DC and DDS HQ. Study participants will be recruited by personal invitation via email by the study's author. The study participants will be directed to the online survey site SurveyMonkey.com.

This study shall have no deception. An adult consent form will precede the online survey that participants complete, and survey completion will not be possible without completion of the adult consent form.

There are minimal potential risks involved with survey participation. These include emotional unease, weariness or indifference. The author of this study is a mandated reporter, and has a duty to report any form of abuse or neglect involving Californians with DD. Survey participants are free to not answer any question that might produce discomfort. Survey answers will be kept confidential and individual answers will not be shared with the RC's, DC's or DDS HQ. All information that could be used to identify survey participants will be kept separately from the research data. Individual identifiers might include age, gender, place of employment, and length of employment. These identifiers will be used for demographic purposes in the methodology portion of the study.

All research data will be stored electronically in a password-protected computer. The list connecting survey participants with their individual identifiers will be kept separately in a locked office in a locked desk drawer. Survey participants may not directly benefit from participation in the survey. The author of the study will be the only individual with access to the survey data. There will not be any voluntary disclosure of the individual identifiers of the survey participants

without their separate consent, except as required by law. The individual identifiers will not be published or used in this or any other study. The author of this study intends to use the data from the survey until it is either published or presented, and then it will be destroyed.

Recommendations

This study was conducted to determine if the public administration system in California is effective not simply at caring for individuals with developmental disabilities, but at actively reducing the number of abuse, neglect and wrongful death incidents that they are involved in. In order to determine incident trends in these categories, extensive research was necessary, as this data is not accessible to the public. After studying past and present research on the subject, it is apparent that more work is necessary.

As previously mentioned by Hughes et al., (2012) the evidence is clear that individuals with developmental disabilities are more prone to abuse and neglect than those without them. As such, states such as California should be concentrating their efforts on providing protections to their most vulnerable citizens. This protection process can be improved upon in two of the following ways.

1. Increase the authority of DDS over the 21 RC's. Because of the 1985 landmark case *Association for Retarded Citizens v. Department of Developmental Services*, DDS power to direct RC spending for programs such as abuse prevention is limited. California political entities and the courts should revisit this decision, as currently DDS is limited in its ability to track & trend incidents statewide, and then follow through on punishments for troublesome vendors on a statewide scale.
2. Chose a statewide abuse and neglect training prevention system. Because of the disjointed way in which services are administered there is currently no universal abuse prevention training in California, as such training decisions are made separately by each

RC and Vendor organization. California should mandate a DD focused abuse and neglect prevention training for individuals with DD and the staff that provide services to them. This would be a step in the right direction and provide a baseline across the system for which DDS could evaluate the effectiveness of any training procedures that it implements.

Conclusion

This study emphasizes the vulnerability of the DD population to being abused, neglected and suffering needless deaths, and focuses on whether or not California has been successful at reducing such occurrences. The study's literature review suggests that the research gap surrounds the relative autonomy of each RC, and the lack of a proven successful DD abuse prevention training that has been implemented in a large state such as California.

In order to further close the study gap it is vital for additional transparency on the occurrences of such instances, and for universal prevention training procedures to be implemented in order for California to better evaluate what is or is not working to prevent Californians with DD from being abused, neglected and dying unnecessarily.

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