Too Little Too Late:
A Call to End Tolerance of Abuse and Neglect

Disability Rights Washington & Columbia Legal Services
November 1, 2012
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EXECUTIVE SUMMARY

Overview

Individuals with developmental disabilities face unacceptable risks of repeated physical harm, psychological trauma, sexual assault and even death because the Department of Social and Health Services (DSHS) does not adequately investigate and effectively respond to abuse and neglect allegations in Washington’s Medicaid-funded Supported Living program.

This report documents the observations of Disability Rights Washington, Columbia Legal Services, and two nationally-recognized abuse and neglect response experts. As detailed in this report:

- **DSHS rarely responds with timely investigations and often entirely fails to investigate** when Supported Living clients are reportedly assaulted, sexually assaulted, or otherwise denied the dignity and care they need and deserve.

- **DSHS seldom holds abusive or neglectful Supported Living employees accountable** or prevents them from having future contact with vulnerable adults.

- **DSHS does not critically review or investigate most unexpected client deaths** to determine whether abuse or neglect may have been a contributing factor.

Recommendations

Washington must stop ignoring the safety of the vulnerable citizens participating in the state’s Supporting Living program. This report explains why Washington should commit to the following reforms:

1. Mandate prompt investigations of abuse and neglect.

2. Allocate sufficient investigators to ensure timely and thorough investigations.

3. Make Supported Living provider requirements more specific.

4. Enhance state regulatory authority to enforce provider certification requirements.

5. Establish an interdisciplinary committee of clinicians, state officials, and stakeholders to review unexpected, suspicious, or potentially preventable client deaths.
BACKGROUND

Who is Disability Rights Washington?

Disability Rights Washington (DRW) is a private non-profit organization that serves as the designated Protection and Advocacy agency for Washington State.¹ Under federal law, every state receiving certain federal funds is required to designate an organization to serve as the Protection and Advocacy System and Washington State has designated DRW.² As a protection and advocacy agency, DRW investigates reports of abuse and neglect of individuals with disabilities, including those with developmental disabilities, and conducts advocacy to ensure that their human and legal rights are protected. For more information about DRW, please visit our website at http://www.disabilityrightswa.org.

Who is Columbia Legal Services?

Columbia Legal Services (CLS) is a nonprofit law firm that protects and defends the legal and human rights of low-income people. CLS has partnered with DRW to represent thousands of persons with intellectual disabilities to assert their rights, including the right to live safely in the community. For more information about CLS, please visit our website at http://www.columbialegal.org.

What is the purpose and scope of this report?

In furtherance of DRW’s mission to “advance the dignity, equality, and self-determination of people with disabilities,” and CLS’s mission to seek justice for low-income clients through systemic change, both organizations issue this report in order to address the ongoing tolerance of abuse and neglect in DSHS’s Division of Developmental Disabilities (DDD) Supported Living program. The primary goal for both organizations is to secure a safe community living option that effectively maintains the health and welfare of the participants who choose Supported Living services instead of institutional care.

This report makes a series of policy recommendations for strengthening the response to abuse and neglect allegations involving Supported Living DDD clients. Although the focus of this report is on Supported Living, the same concerns discussed in this report may be present for DSHS oversight of other kinds of community and institutional providers and applicable to law enforcement or other agencies charged with responding to abuse and neglect. This report is not intended to be a substitute for any examinations or recommendations by any clients, advocates, task forces, or committees reviewing the incident response and oversight systems for any setting where people with disabilities are at risk of abuse or neglect.³

Finally, the purpose of this report is not to suggest or in any way support the idea that people with developmental disabilities ought to be institutionalized for their safety. DRW and CLS have not recently conducted a systemic investigation into the adequacy of the response to

¹ RCW 71A.10.080
³ There are at least two work groups currently examining abuse and neglect of vulnerable adults in Washington: the Adult Family Home Quality Assurance Panel and the Abuse/Neglect of Adults Who Are Vulnerable Study Group.
abuse and neglect in institutions, and this report provides no basis for comparison between community and institutional services.

**What is Supported Living?**

About three thousand adult individuals with developmental disabilities who could choose to live in state-run institutions have chosen to live in their own homes with the help of in-home support staff. The people who assist them are employees of state-certified “Supported Living” provider agencies, most of which contract with DDD. DDD uses state and federal funding, primarily under the federal Medicaid program, to pay for Supported Living services.

Supported Living clients depend on their state-certified providers to hire, train, and supervise the staff they need to assist them with everyday tasks, help them maintain safe and healthy lifestyles, and provide them with habilitation services to gain independent living skills. All Supported Living clients have a qualifying developmental disability, but many also have physical disabilities as well as co-occurring mental health conditions. While some Supported Living clients need only a few weekly service hours, others need care and supervision twenty-four hours a day. Many Supported Living clients have complex medical or behavioral support plans, and rely on their Supported Living providers to implement these plans to keep them safe and healthy.

**Why are state abuse and neglect investigations important?**

Without improvements to abuse and neglect responses, Supported Living clients will continue to be at risk. Below are three recent cases demonstrating why improvements are critically needed.

1. On July 4, 2012, a Seattle news station reported the police found a young Supported Living client wandering near a busy intersection partially clothed, eating grass. When the police identified the man and went to his residence, they found his Supported Living care provider passed out drunk in a dirty home littered with garbage, broken glass and an overflowing clogged toilet. Although the man’s care plan called for constant supervision, this was the third time in less than three years the man had been permitted by his caregivers to leave home without supervision and without their knowledge. The young man’s father had also noticed his son losing weight and coming to weekly family dinners with bruises and cuts the provider could not explain. Although the father speaks little English, he tried to advocate on his son’s behalf, but his

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4 While most Supported Living provider agencies are contractors, a small minority of Supported Living clients receive services from the State Operated Living Alternative (SOLA) program. SOLAs are operated by DDD but are certified and subject to the same regulations as the privately owned and operated Supported Living provider agencies. The SOLA program in King County was recently discussed in local news report, “Repeat Violations Threaten Shutdown of 13 state-run group homes”, available at [http://www.king5.com/news/investigators/Repeat-violations-threaten-shut-down-of-group-of-state-run-group-homes-174864591.html](http://www.king5.com/news/investigators/Repeat-violations-threaten-shut-down-of-group-of-state-run-group-homes-174864591.html).

complaints and concerns received little attention from the DDD case manager or Supported Living provider.

Without adequate state oversight of the Supported Living provider’s services, his father fears the injuries will continue to occur, or that his son will again leave his home unaccompanied. His father lies awake at night worrying about his son wandering the streets alone, explaining in a translated statement to DRW, “I could not help but imagine what could happen to my son since he has such little ability to keep himself safe in traffic or with strangers.”

2. Two brothers moved out of a large institution and into their own independent homes, where they took advantage of their new and varied experiences in the community. They started doing things like taking bus rides and socializing with local shopkeepers. Due to serious medication errors by a Supported Living Provider, one brother was hospitalized after acquiring significant brain damage and was forced to return to the institution. The second brother remained in the community, but was hospitalized last year due to a serious medication error by the same Supported Living provider. Although this error was reported to DSHS, the state failed to investigate whether any individual employees were responsible. Instead, DSHS investigated to determine whether the provider’s practices were compliant with Supported Living requirements. The provider’s records documented at least six medication errors for this client occurring in the three months prior to the error that resulted in his hospitalization, yet DSHS issued no citation for failing to ensure proper implementation of his medication plans. With no required plan of correction to address medication administration practices, the provider continued to make medication errors. Over the course of the next year, the client’s records showed seven more medication errors.

The third brother of the two DDD clients serves as their legal guardian. In his statement to DRW, he explained “I fear that without proper oversight by the state, [the provider] will continue to make these same types of medication errors and that one day [my brother] will end up like [his other brother], institutionalized and completely dependent on others.”

3. In April 2012, a Supported Living client reported to his job coach that one of his Supported Living staff had sexually assaulted him that morning. Although the allegations were reported to the state within hours, a week went by before any state investigation began. No one took the client to have an immediate medical evaluation conducted the day he reported the assault. The provider also downplayed the extent of his allegations when informing the client’s family, stating the client had alleged being “pinched” by a staff person the provider was unable to identify.

When the client’s niece learned he had actually reported being sexually assaulted by a named staff person, she went to check on him. She told DRW she found he was “truly terrified.” She explained, “My family and I do as much as we can to protect [my uncle] from harm, but we have to rely on a system to swiftly and aggressively respond when something as serious as sexual assault is reported.”
WASHINGTON’S FAILURES TO PROTECT SUPPORTED LIVING CLIENTS

What problems did DRW and CLS’s monitoring expose?

For several years, DRW and CLS have been concerned about the abuse and neglect response system for people with disabilities. Since 2010, after the death of a Supported Living client captured front page headlines in the Tacoma News Tribune, DRW and CLS have been intensively monitoring Washington’s response to allegations of abuse and neglect by Supported Living providers. With pro bono assistance from the law firm of Perkins Coie LLP, DRW and CLS reviewed a random sample of Supported Living incident reports, case management notes, investigation files, and provider records. DRW and CLS also reviewed investigation and complaint data produced by DSHS. DRW and CLS also visited and interviewed dozens of Supported Living clients living in various communities across Washington State, as well as many family members and Supported Living providers.

Based on its monitoring, DRW and CLS reached the following conclusions:

- Nearly half of the abuse and neglect allegations in the records sample were never investigated by DSHS.
- When an investigation was actually conducted, DSHS often took weeks or months to begin reviewing serious allegations of abuse or neglect.
- DDD Case managers rarely made contact with clients after serious health and safety incidents were reported to evaluate their clients’ safety or verify implementation of the provider’s protection plans.
- DSHS rarely made findings of abuse or neglect against individual employees, even with eyewitness statements documented in the state’s own investigation files. In one case, employees reported witnessing their co-worker stomp on a client’s genitals while calling the client profane names, but DSHS did not sanction the employee or the Supported Living provider.
- Supported Living providers often had to make decisions about hiring, firing or retaining employees accused of abuse or neglect without the benefit of a state investigation, and were often uncertain about what DSHS expected them to do in order to protect their clients from abuse and neglect.
- Many Supported Living clients who were dissatisfied with the quality of their services, as well as their guardians and family members, were surprised to learn there may be other options for obtaining Supported Living services from other providers. Some believed their case managers had indicated to them they could not change providers.

7 “Justice for his brother David” The News Tribune (October 24, 2010) and “Family Unhappy with Group Home’s Handling of Daughter” The News Tribune (October 24, 2010) reporting heat related death and near-death allegedly due to a Supported Living provider’s neglect during a record-breaking heat wave.
**What did the nationally recognized experts find?**

In 2012, DRW and CLS hired two nationally-recognized experts in abuse and neglect of people with disabilities to evaluate Washington’s responses to alleged abuse and neglect in its Supported Living program.

Both experts, Sue A. Gant, Ph.D and Nancy K. Ray, Ed.D, have worked in other states to improve systems for protecting clients from abuse and neglect and improving community-based services. Dr. Gant specializes in program development and evaluation of services for persons with developmental disabilities. Dr. Ray specializes in the provision of monitoring services, including the design of quality assurance systems and conducting studies regarding government oversight and fiscal accountability standards of health care programs for the elderly and persons with disabilities.

These experts issued detailed reports with their findings and supporting data, the publicly disclosable portions of which are attached with client names and confidential information omitted. Based on their independent reviews of the state’s investigation records from the June through August 2011 and Mortality Review records from June through December 2011, Drs. Ray and Gant made the following findings:

- When DSHS conducted investigations into allegations of abuse and neglect, it rarely made any attempt to determine whether the alleged individual perpetrator committed the reported misconduct.

- A chronic backlog of abuse and neglect complaints overdue for investigations was critically compromising client safety and integrity of investigations.

- Investigation and mortality review files consistently lacked adequate documentation of key evidence, such as witness interviews, medical and provider record reviews, and client observations.

- State records documented ongoing unresolved health and safety issues, injuries of unknown origins, and unaddressed employee errors in providing necessary care.

- Several unexpected and suspicious client deaths were never formally investigated for potential abuse or neglect.

- Cursory reviews by the state of potentially preventable client deaths failed to identify necessary improvements to service quality and client safety.

- Inadequate investigation protocols and mortality review policies were cultivating inconsistency and delayed responses to serious incidents.

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8 See Experts’ Curriculum Vitae attached in Appendix A.
9 See Appendices B and C.
RECOMMENDATION NO. 1:

MANDATE PROMPT INVESTIGATIONS OF ABUSE AND NEGLECT

Recommendation:

DSHS should be required to adhere to appropriate deadlines for initiating and completing investigations of abuse or neglect.

Rationale:

A client who has been reportedly sexually assaulted, assaulted, or dangerously neglected should not have to wait weeks for DSHS to start an investigation to determine whether there is sufficient evidence to substantiate the event or whether the Supported Living provider failed to comply with DSHS rules. For the many reasons Dr. Ray outlined in her report, it is crucial for investigations to begin promptly:

Why It Is Poor Practice to Delay Initiation of Investigations

- Victims who have disabilities may forget what happened or be unable to recount what happened consistently.
- Physical evidence may be lost.
- The scene of the incident may no longer be intact.
- Any injuries to the victim may have healed and no longer be visible.
- Witnesses may also forget or “go missing.”
- Alleged perpetrators may not be around any longer.
- Alleged perpetrators have time to re-construct their “stories” of what occurred.
- Victims feel abandoned by long delays in investigating.
- Delays in investigating discourage reporters from filing reports.

To avoid these problems, some states require investigations of major incidents to begin within twenty-four to forty-eight hours.¹⁰

Recommendation No 1. – Continued

By contrast, the earliest that DSHS’s policies require an investigation to begin is two working days after DSHS receives the complaint, even if the incident involves a life-threatening situation. For life-threatening incidents occurring on Fridays or holidays, an investigation prioritized for two working days could start up to four or five days after the incident was reported and still satisfy DSHS policies.

For investigations of a Supported Living provider’s alleged noncompliance with state rules, DSHS usually assigns starting deadlines of ten or twenty working days excluding weekends and holidays. These deadlines translate into two or four weeks to start the investigation. Washington, unlike most states, has a bifurcated abuse and neglect investigation system that assigns a second investigation to determine whether to find a specific individual Supported Living employee committed the alleged act of abuse or neglect. DSHS’s deadlines for starting investigations into allegations of abuse and neglect against individual Supported Living employees are even more delayed, ranging from ten to sixty days.

In Dr. Ray’s experience, most states require all abuse and neglect investigations to be completed within 30 days. Washington only has policies on how quickly Supported Living provider and Supported Living employee investigations must be started and no requirements about how quickly investigations must be completed. Dr. Ray found that almost all DSHS investigations into allegations of Supported Living employee abuse or neglect were not completed within 30 days and a significant number were not completed within 90 days.

DSHS must adhere to deadlines that require it start Supported Living abuse and neglect investigations more quickly and finish them more quickly. Otherwise, Supported Living clients will continue to be victimized not only by individual perpetrators and negligent providers, but by the current ineffective abuse and neglect response system.
RECOMMENDATION NO. 2:
ALLOCATE SUFFICIENT INVESTIGATORS
TO ENSURE TIMELY AND THOROUGH INVESTIGATIONS

Recommendation:

DSHS must have more investigators in order to timely investigate the current and growing volume of Supported Living abuse and neglect complaints.

Rationale:

Public awareness of the importance of reporting abuse and neglect has grown in recent years. The number of complaints DSHS has received about Supported Living providers has almost doubled since 2008. The number of complaints assigned for investigation of alleged abuse and neglect committed by individual Supported Living employees has nearly tripled.

In its budget-request documents, DSHS admits that Supported Living clients will be at “increased risk of harm” if the state does not allocate additional investigatory resources. As DSHS explains, the shortage of investigators is keeping DSHS from being “able to meet the increasing workload demand” and is increasing the risk that perpetrators will “continue to work in long-term care settings and [will be] less likely to be investigated.”

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12 Department of Social and Health Services 2013-2015 Biennial Budget Long Term Care, p. 143 (online references above in FN 10).  
13 2012 Reduction Options and Supplemental Budget Request, p. 335; 2013-2015 Biennial Budget Long Term Care, p. 145 (online references above in FN 10).
DSHS’s Supported Living provider noncompliance investigation Complaint Logs show a backlog of uninvestigated complaints about noncompliant provider practices. According to these logs, investigations of alleged noncompliance by Supported Living providers frequently do not begin by the state-assigned deadlines. As of August 2012, there were 214 complaints due for an investigation to start, but over half of these had not yet been initiated. Most of the overdue complaints were more than 90 days past their initiation deadlines.

As discussed above in Recommendation No. 1, DSHS should be required to start investigations more quickly. If DSHS cannot begin investigations within its current lax start dates, it cannot be expected to keep up with the growing numbers of complaints. As time goes on, more and more investigations will be compromised as additional time fades memories, erodes witness credibility, and evidence is lost or destroyed.

In addition, Complaint Logs show that during the past two years DSHS closed a total of 2,950 complaints about substandard Supported Living provider practices. DSHS closed over a thousand of these backlogged complaints without conducting any investigation at all, despite the fact that DSHS staff determined that the complaints involved allegations that Supported Living clients’ health and safety were at risk.
Recommendation No. 2 – Continued

Finally, Dr. Ray found that the state hardly ever conducts these investigations of individuals alleged to have abused or neglected a Supported Living client within any timeframe that would allow for an adequately reliable investigation. These investigations of Supported Living employee misconduct are necessary to ensure that employees who commit abuse and neglect are prohibited from working with Supported Living clients. However, Dr. Ray found that nine to twelve months after abuse or neglect was alleged, there was still no documentation of any review of employee misconduct being initiated for eighty-five percent of incidents. In a handful of cases, she found there had been an administrative record review, but no formal investigation.

These failures to initiate timely investigations of Supported Living providers or their employees demonstrate there are insufficient resources currently devoted to abuse and neglect investigations. For client safety, it is imperative that the state devote additional resources to conduct prompt and thorough abuse and neglect investigations.
RECOMMENDATION NO. 3:
MAKE SUPPORTED LIVING PROVIDER REQUIREMENTS SPECIFIC

Recommendation:

The rules that specify a Supported Living provider’s responsibility to prevent abuse and neglect must be more specific and contain objective criteria for evaluating provider compliance.

Rationale:

The certification requirements for Supported Living providers codified in Washington Administrative Code (WAC) 388-101 specify very little about what providers must include in their policies for responding to allegations of abuse or neglect, besides requiring employees to report the incident to the state.

<table>
<thead>
<tr>
<th>Washington Administrative Code 388-101-4170</th>
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<tr>
<td>(1) The service provider must develop, train on and implement written policies and procedures for:</td>
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<tr>
<td>(a) Immediately reporting mandated reporting incidents to:</td>
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<td>(i) The department and law enforcement;</td>
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<td>(ii) Appropriate persons within the service provider’s agency as designated by the service provider; and</td>
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<td>(iii) The alleged victim's legal representative.</td>
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<td>(b) Protecting clients;</td>
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<td>(c) Preserving evidence when necessary; and</td>
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<td>(d) Initiating an outside review or investigation.</td>
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(2) The service provider must not have or implement any policies or procedures that interfere with a mandated reporter's obligation to report

DSHS provides no specifics for providers regarding what they must actually do to meet the regulation’s requirement that they “protect clients,” “preserve evidence,” or “initiate an outside review or investigation.” The lack of specificity results in inconsistent practices and enforcement. For example, while some Supported Living providers have policies that almost always require suspension of any employee suspected of abuse or neglect in order to protect clients, other providers have no written criteria to assess whether to suspend the employee. Some Supported Living providers conduct their own internal investigations into employee misconduct, while other providers have policies explicitly forbidding any self-investigation or internal review so as to avoid tainting official state or law enforcement investigations. DSHS has not adopted any rules requiring or forbidding internal investigations, nor has it adopted any rules that tell providers how internal investigations should be conducted.
Recommendation No. 3 – Continued

The Supported Living rules also do not specify the extent of Supported Living Providers’ responsibility to prevent abuse and neglect. The rules for Adult Family Homes and Supported Living providers recognize clients have the right to be free from abuse, neglect, abandonment, and exploitation. However, while Adult Family Home providers are required to “ensure” this right for each resident and “ensure that staff do not abandon, abuse, neglect, seclude, exploit or financially exploit any resident,” Supported Living rules only require that Supported Living providers “promote and protect” this right and contain no requirements for a Supported Living provider to ensure employees do not commit abuse or neglect. Protecting and promoting client rights is not the same thing as ensuring client rights. And, while DSHS’s Adult Family Home and Assisted Living rules make providers liable for allowing misconduct by their employees, Supported Living rules do not. There is no reason why DSHS should treat Supported Living clients as second class citizens in this way.

Finally, the Supported Living rules do not prohibit a Supported Living provider from hiring or retaining someone found to have abused or neglected a vulnerable adult. Adult Family Homes, Assisted Living Facilities, and Nursing Homes are all prohibited from doing so. Supported Living providers may employ individuals found by DSHS to have abused or neglected a vulnerable adult so long as the employee does not work unsupervised with Supported Living clients. Nothing in the Supported Living certification regulations define who must supervise the employee, or what level of supervision is required.

DSHS should be required to adopt rules that protect Supported Living clients to the same extent that DSHS rules protect clients in other settings.

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14 WAC 388-101-3320; WAC 388-76-10670.
15 WAC 388-76-10680; See also WAC 388-78A-2660 (requiring that assisted living facilities “not allow any staff person to abuse or neglect any resident”); WAC 388-97-0640 (requiring nursing facilities “not allow staff to engage in” abuse or neglect).
16 WAC 388-101-3320.
17 WAC 388-101-3250(8): Supported Living providers must prevent unsupervised access, but are permitted to hire persons with disqualifying convictions, pending criminal charges, or a substantiated finding of abuse or neglect.
18 Adult Family Homes: WAC 388-76-10180; Nursing Homes: WAC 388-97-1820; Assisted Living Facilities: WAC 388-78A-24641 (filed October 18, 2012; effective date 31 days after filing).
RECOMMENDATION NO. 4:
ENHANCE STATE REGULATORY AUTHORITY TO ENFORCE PROVIDER CERTIFICATION REQUIREMENTS

Recommendation:

DSHS must have the same authority to enforce Supported Living rules as it does to enforce its rules for other long term care settings.

Rationale:

Adult Family Homes, Assisted Living Facilities, and Nursing Homes:

- Pay a licensing fee that helps pay for the cost of DSHS staff who inspect and investigate them
- Can be fined by DSHS for violating DSHS rules
- Can have admissions halted by DSHS.

None of the above apply to Supported Living providers. All DSHS can do, short of revoking a Supported Living provider’s certification when the provider is found to have violated DSHS rules, is place the provider on “provisional certification.” Even Supported Living providers placed on provisional certification pay no additional re-certification fees or fines, despite the fact that it takes additional state resources to monitor their compliance.

ENFORCEMENT REMEDIES

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<th>Supported Living</th>
<th>Adult Family Home</th>
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<td>Provider Corrective Action Plans</td>
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Supported Living providers who violate DSHS rules usually face no significant consequences, because DSHS has no intermediate sanctions to leverage against the provider. DSHS has only the “death penalty” available to it, i.e., it can only revoke the provider’s certification. Several Supported Living providers serve hundreds of clients. Revocation of any provider’s certification would risk client displacement and loss of necessary community services, which makes these large providers, in a sense, too big to fail. Remedial measures short of full decertification must be provided.

19 See WAC 388-101-4190.
Recommendation No. 4 – Continued

Other Supported Living providers serve clients who need specialized behavioral support or who are medically fragile. DSHS would be hard-pressed to find these clients other providers. Without intermediate sanctions, DSHS has no real tools for addressing provider noncompliance.

DSHS needs to have a range of flexible Supported Living enforcement options, just as it does with Nursing Homes, Adult Family Homes, and Assisted Living Facilities. To the extent that legislative action is necessary to permit DSHS these options, the Legislature should act in the 2013 session to provide that authority.
RECOMMENDATION NO. 5:

ESTABLISH AN INTERDISCIPLINARY COMMITTEE OF STATE OFFICIALS, CLINICIANS, AND STAKEHOLDERS TO COMPREHENSIVELY REVIEW UNEXPECTED, SUSPICIOUS, OR POTENTIALLY PREVENTABLE CLIENT DEATHS

Recommendation:

Washington needs a transparent and accountable mortality review process that completes thorough and accurate reviews of all unexpected and suspicious Supported Living client deaths.

Rationale:

A meaningful review of Supported Living client deaths affirms the value of all human life and the principle that every individual deserves the care and treatment they need to survive – regardless of whether or not they have physical or intellectual disabilities.\(^{20}\)

Although Washington has a formal mortality review process, Dr. Gant found that Washington’s implementation of that process is so cursory and irregular that it is ineffective as a safeguard for protecting client welfare. She found that Washington subjectively selects which client deaths to review, and is not implementing a process for reviewing a consistently comprehensive set of information. For instance, over half of the mortality review files reviewed failed to even include the client’s death certificate.

Autopsies are rarely conducted to determine the cause of the unexpected deaths of Supported Living clients that the Mortality Review Committee examines. The few times when the Mortality Review Committee indicated an autopsy was conducted for client deaths occurring during the time period Dr. Gant reviewed -- between June and December of 2011 -- the Mortality Review Committee did not obtain a copy of the autopsy report or demonstrate that anyone on the Committee had reviewed the autopsy results.

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Recommendation No. 5 – Continued

However, in several client deaths the Committee reviewed, the Committee made no explicit allegations of specific Supported Living employee misconduct or provider noncompliance with DSHS rules, but the circumstances of the clients’ deaths were suspicious and raised serious questions about whether abuse or neglect had been a contributing factor (i.e. questions regarding timely access to healthcare from medical professionals, level of client’s supervision and staff attentiveness, staff reactions to finding clients nonresponsive, and validity of Do Not Resuscitate orders). However, most of these deaths reviewed by the state’s Mortality Review Committee were not investigated to rule out abuse or neglect.

While the Mortality Review Committee made no referral for an abuse or neglect investigation in many cases, there was at least one death, in July 2011, where DSHS did not start an investigation into the client’s death until March 2012. In that case, DSHS substantiated a specific allegation of neglect against a Supported Living employee, but did not do so until late June 2012 -- nearly a year after the client’s death. While DSHS found the employee neglected the client by failing to immediately call 911 or perform CPR in accordance with her training, the Supported Living provider was not sanctioned or required to take any remedial action.

One of the most glaring deficiencies in Washington’s Mortality Review process is the repeated failure to answer essential questions regarding the individual’s care and cause of death. For example, in cases where Aspiration Pneumonia was identified as a contributing factor for the individual’s death, there was no or very little analysis of the aspiration incident that caused the pneumonia and whether providers needed to improve their precautionary measures to prevent pneumonia-prone clients from choking. There were a number of other individuals who died completely unexpectedly in the care of their Supported Living provider, but the mortality review process made little attempt to identify the causes of their unanticipated deaths. For the death of one individual who had no serious or terminal conditions, the Mortality Review Committee listed the primary cause as “other,” which it further described as “Down Syndrome” and “Hyperlipidemia.” Down Syndrome is not a recognized cause of death and hyperlipidemia, which is essentially high cholesterol, is a condition that ordinarily, by itself, is not fatal. DSHS simply failed to analyze why a Supported Living client with high cholesterol, a condition that millions of Americans have and are treated for, died unexpectedly.
Recommendation No. 5 – Continued

As recommended by the Government Accountability Office (GAO) and the federal Centers for Medicare and Medicaid Services (CMS), many states implement a multi-disciplinary mortality review process to identify ways to improve client safety and service quality. In Minnesota, for example, state law mandates that a multi-disciplinary committee of clinicians and stakeholders conduct a medical review of client deaths. Washington’s Mortality Review Committee for Supported Living client deaths is comprised solely of DSHS’s DDD employees with no participation by outside clinicians or stakeholders.

Washington’s current Mortality Review policies and process must be reformed. DSHS should be required to establish an interdisciplinary Mortality Review committee that includes outside stakeholders and clinicians.

21 See MINN. STAT. 245.97 (2008).
I. Current Employment

2001 - Present  President, NKR & Associates, Inc.

A consultation corporation specializing in the provision of monitoring services in conjunction with class action law suits, administrative sanctions of state governments, and corporate integrity agreement issued by the U.S. Office of the Inspector General. NKR & Associates has a full time staff, including experts in the design of quality assurance systems, conduct of trend studies of abuse, neglect, reportable incidents and deaths, nursing and clinical services, the precepts of governmental regulatory oversight and fiscal accountability standards for most health care programs for the elderly and for persons with disabilities. In addition, the firm has specialized in the development of technical assistance and management strategic plans to assist health care companies achieve compliance with Court Orders and federal and state governmental standards.

II. Education

John F. Kennedy Institute for Government Executives, Harvard University, 1986
Doctorate of Education, State University of New York at Albany, 1978
Masters of Education, State University of New York at Albany, 1972
Bachelor of Arts, Duke University, 1970

III. Expert Consultant Experience

Current Clients

2001  Monitor, United States v. State of Tennessee et. al. (Arlington Developmental Center)
Western District of Tennessee, Civil Action No. 92-2062-M1/A**

2011  Monitor for Department of Justice, CRIIPA Division, Georgia State Hospitals

2011  Consultant, Department of Justice, Criminal Fraud Division

2011  Washington Disability Rights, Protection from Harm

2011  Protection from Harm Consultant State of Oregon Medicaid Agencies

Recent Clients

2008  Protection from Harm Consultant State of Oregon Medicaid Agencies

2001 - 2007  Monitor of the Corporate Integrity Agreement between the HHS Office of Inspector General and Twin Oaks Nursing Care Center
2000 - 2009 Protection from Harm Consultant State of Ohio Department of Mental Retardation and Developmental Disabilities

2000 - 2004 Monitor of the Corporate Integrity Agreement between the HHS Office of Inspector General and Brentwood Behavioral Health Company

2001 - 2002 Court Expert, Goebel v. Colorado Department of Institutions (Class Action: re: community mental health services in Denver; temporary Court appointment to conduct an independent evaluation of the State's compliance with a 1993 Settlement Agreement)**

2000 - 2001 Consultant, Commission on Mental Health Services, Washington DC (To conduct an evaluation of the District's assertive community action treatment teams for persons with serious mental illness)

1999-2000 Expert Consultant, Center for Public Representation, Rolland v. Celluci, Federal District Court of Western Massachusetts (Class Action re: persons with developmental disabilities inappropriately placed in nursing homes)**


1998-1999 Monitor of the Corporate Integrity Agreement, United States of America v. Charter Hospital of St. Louis (Class action by HHS Inspector General re: financial and treatment practices at a private psychiatric hospital)

1998 Consultant, Department of Juvenile Justice, State of Georgia: regarding a statewide quality assurance and abuse and neglect investigation system


1996-1999 Consultant to the Monitor, Arnold v. Sarn, a community class action settlement regarding services to adults with serious mental illness in Phoenix, AZ

1996-2000 U.S. Department of Justice, Civil Rights Division (Re: Louisiana juvenile detention facilities and constitutional standards for rehabilitation and protection from harm; Re: New Mexico School for the Vision Impaired and constitutional standards for habilitation and protection from harm; Re: G. Pierce Wood Hospital**)


1996 The Center for Mental Health, Washington D.C. (Re: design of a quality management, utilization review, and management information system for a large multi-faceted mental health outpatient program)

** References cases where court testimony or depositions have been given
1995-1998 Consultant, State of Hawaii, Department of Health, Hawaii State Hospital (Re: appropriate treatment planning and therapeutic programming, protection from harm, and the use of restraint and seclusion)


1995 State of Oregon, Fairview Training Center (Re: appropriate prevention and response to allegations of abuse and mistreatment of residents)

1995 Swidler and Berlin, Hunt v. Mesaros, U.S. District Court of Maryland (Class Action re: Great Oaks Center, a state institution serving persons with developmental disabilities)

1993-1997 Federal Court Monitor, Jackson v. Ft. Stanton in U.S. District Court for the District of New Mexico (Class Action re: state centers for persons with developmental disabilities)


1987-90 Expert Consultant, Lelsz v. Kavanagh, U.S. District Court of the Northern District of Texas (Class Action re: state schools for persons with mental retardation)**

IV. Previous Employment

1979 - 1995 NYS Commission on Quality of Care for the Mentally Disabled
1993 - 1995 First Deputy and Policy Research Director
1980 - 1992 Policy Director and Special Assistant to the Chairman
1979 - 1980 Staff Training Development Specialist

1978 - 1979 NYS Board of Social Welfare, Research Associate

1975 - 1978 State University of New York at Albany, Research Associate and Lecture
1970 - 1974 Hilo, Hawaii and West Seneca, New York, First Grade Teacher

V. Published Works

"Capitalizing on the Safety Net of Incident Reporting Systems in Community Programs" in Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities, New York, 1994


"Restraint and Seclusion Usage Among NYS Psychiatric Facilities." Psychiatric Services, October 1995 (second author, Mark Rappaport)

**VI. Reports Submitted as an Expert Reviewer/Witness and Court Monitor**

*United States v. State of Tennessee et. al. (Arlington Developmental Center)* Western District of Tennessee, Numerous monitoring reports regarding community services, institutional care, abuse and neglect trends, etc.

*Goebel v. Colorado Department of Institutions*, A Review of the State of Colorado's Compliance with the Goebel Settlement Agreement and Services Plan, September 2000

*People First v. Clover Bottom et. al.*, Trend Studies of Abuse and Neglect, Deaths, Serious Injuries, Elopements Occurring Community Programs for Persons with Developmental Disabilities

*Rolland v. Celluci*, Individuals with Developmental Disabilities Residing in Massachusetts' Nursing Facilities, February, 1999 and Individuals with Developmental Disabilities/Mental Retardation Residing in Massachusetts' Nursing Facilities, July 1999

*CTBI v. Hogan*, A Review of Basic Care ...... of Individuals with Brain Injuries in Connecticut State Mental Health Institutions, 1998


**VII. Major Government Publications**

**A. Quality Assurance Reports**


Tennessee Division of Mental Retardation Services, Substantiated Reports of Class Member Abuse, Neglect, Exploitation and Other Mistreatment (2003, 2004, 2006)
A Review of Elopement Incidents Among Tennessee DMRS Community Class Members, 1999

An Assessment of Maricopa Correctional Health Services’ Implementation of the Quality Management Plan Required by the *Arnold v. Sarn* Settlement, 1999

An Independent Review of Maricopa County’s Services for Adults with Serious Mental Illness (with Martha Knisley), 1998

Quality Management Plan for Inpatient Psychiatric Services for Maricopa Correctional Health Services, 1997

**B. Services for Persons With Developmental Disabilities**


A Review of Familial Abuse of Adults with Developmental Disabilities (1992)


Enhancing Family Support Services for the Developmentally Disabled (1985)

Promoting Equity in the Family of New York: Outpatient Services for Developmentally Disabled People (1984)

The Incident Reporting and Review System: More Process Than is Due (1983)


The Endless Quest: The Autistic and Their Families (1981)

**C. Services for Children**

Watching Over the Children: Commission Activities on Behalf of Children with Mental Disabilities (1994)

NYS Residential Services for Children with Emotional Problems: Call for Reform (1993)

Child Abuse and Neglect in NYS Mental Health and Mental Retardation Residential Programs (1992)

Investigation into Allegations of Child Abuse and Neglect at Western New York Children’s Psychiatric Center (Interim Report, 1989; Final Report, 1990)

**D. Discharge Planning for Persons with Mental Illness**

Falling Through the Safety Net: Community Living in Adult Homes for Patients Leaving Psychiatric Hospitals (1993)


E. Restraint and Seclusion

Voices From the Frontlines: Patients' Perspectives of Restraint & Seclusion (1994)

F. General Mental Health Issues

Breaking with the Past: How New York's Private Psychiatric Hospitals Have Managed Since Managed Care (1996)
Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation (1990)
NYS Outpatient Mental Health Services: A Cost and Program Review (1989)
Outpatient Suicide: A Study of 172 Suicides Reported by New York State Mental Health Programs in 1982 (1988)
The Multiple Dilemmas of the Multiply Disabled: An Approach to Improving Services for the Mentally Ill Chemical Abuser (1986)
Psychotropic Drug Usage: A Rx for Improvement -- A Study of Selected NYS Psychiatric Centers (1983)

VIII. Community Service

Parsons Child and Family Center, Board of Directors (1997 - 2000)
Hudson River Center for Program Development, Board of Directors (1995 - 2000)
Citizen Planning Committees, Bethlehem School Board (1998 - 1999)
Vice President, Board of Directors Schools Out, Inc. (1985 - 1988)
Board of Directors Albany YWCA (1981 - 1984)
Chairperson of the Selections Committee for the Capital District's YWCA Tribute to Women Event (1983)
Curriculum Vitae

Sue A. Gant, Ph.D.
Gant, Yackel & Associates Inc.
2015 Parkview Dr.
Hawarden, IA 51023

FID # 06-1150626
Tel: (712) 551-3979
Fax: (712) 551-3758

Education

9/64 - 6/67 West Sioux Community High School, Hawarden, Iowa
Awarded Diploma.


1/69 - 6/71 University of South Dakota, Mental Retardation and Special Education.
Awarded B.A.

6/71 - 8/71 University of South Dakota, 12 semester hours: Graduate level; Emphasis: Mental Retardation.

9/71 - 8/72 Southern Illinois University, Therapeutic Recreation, Developmental Disabilities.
Awarded M.S.

6/74 - 5/78 Southern Illinois University, 113 semester hours: Educational Psychology - Human Learning and Behavior Analysis; Developmental Disabilities Program Development and Evaluation.
Awarded Ph.D.

1/89 Connecticut Department of Administrative Services, 24 hours: Course in Labor Relations Certificate


1989-2011 CEUs from annual conference, workshops and training institutes. A sample of other postgraduate educational experiences by subject matter can be found in the training section of this resume.

Experience

9/89- Present Employed by Gant, Yackel & Associates Inc. as a consultant in human service matters with specialization in program development and evaluation, monitoring civil rights litigation and policy analysis.
12/07-Present  Rule 706 Expert to the Court in *Jackson et. al. vs. Fort Stanton et. al.*, (Civil Action No. 87-0839), Honorable James P. Parker, United States District Court for District of New Mexico.

Under the Federal Rules of Evidence the trial Judge has the inherent powers to appoint expert witnesses. In December 2007 I was appointed by Judge Parker to assess the State of New Mexico’s compliance with several court orders and stipulated agreements to ensure that the State of New Mexico meets the individualized needs of a class of New Mexico citizens with developmental disabilities and facilitate efforts of the parties to achieve compliance with the orders. The *Jackson* class action involved a class of approximately 500 individuals with developmental disabilities, who were institutionalized at the Los Lunas or Fort Stanton Training School. There are approximately 320 living class members that now reside in small community settings throughout New Mexico. New Mexico community services are funded through the Medicaid Home and Community Based Waiver (HCBW). Class members are adults with developmental disabilities and handicapping conditions including complex medical needs, behavioral and psychiatric challenges, and sensory, physical and intellectual impairments.

4/95-2/00  Federal Court Monitor in the matter of the *United States of America vs. State of Oregon*.

In April 1995 the parties agreed to my appointment to oversee the implementation of a 1987 consent decree about conditions at Fairview Training Center. My responsibilities included monthly review of individual class members who were at significant risk of harm, consultation to interdisciplinary teams, and compliance monitoring. In addition, I monitored the development and implementation of discharge planning for community placement and provided guidance to the management of this 600-bed institution. The Legislature passed a budget June 1997 that supported facility closure by the year 2000. Many improvements in the care and treatment of individuals at this facility occurred over the years. The facility had a sound behavior support policy and became restraint free for a number of years. Discharge to community settings progressed with a census of 225 people in 12/98 and the last person was placed in February 2000. Many of the last persons to be placed required extraordinary supports due to challenging psychiatric illnesses and/or complex medical needs.


Provided direct support to hurricane victims and supervised outreach workers who provided services to private citizens in their homes and students and teachers in public schools.
Executive Assistant to the Commissioner of the Connecticut Department of Mental Retardation (DMR) with 9,000 recipients.

Directed the staff and operations of the DMR Quality Assurance Division; reviewed facility and community based residential and day programs for quality and recommended strategies for quality improvement and regulatory compliance; system of quality assurance addressed service planning, service delivery, health and safety, participant rights and safeguards, and financial/program accountability for services delivered by licensed residential providers, and contracted supported living, day services, and supported employment to all individuals supported by DMR; Program Quality Reviews by self advocates, community members, and DMR staff; Regional and State level Mortality Review; formulated program goals and objectives; developed or assisted in the development of related policy and regulations; monitored plans and policy to conform to federal, and state accreditation standards; interpreted and administered pertinent laws; evaluated staff; planned and implemented through research the reporting and analysis of data compiled on the quality of life experienced by recipients of services. In consultation with contractor, Touche Ross Consulting, participated in the development of CAMRIS (Connecticut Automated Mental Retardation Information System), DMR’s internal mainframe data management system; designed data menus and reports to be generated through CAMRIS. Reports used to monitor quality of DMR services. Produced reports and presented to the Court compliance status in Connecticut Association for Retarded Citizens v. Thorne (Implementation Plan status- community services development) and United States of America v. State of Connecticut (improvement in conditions at one large segregated facility).


Served as an expert to the Court to ensure implementation of the Court's 1976 Order in the matter of Gary W. (Texas Children's Case) that mandated the return of 684 poor and/or handicapped Louisiana children placed in Texas facilities to their home state. Placement was to have been accomplished using the legal principle of "least restrictive" environment and planning was to have been predicated on individual assessment results. The 684 class members, mostly young adults by 1980, had characteristics including mental retardation of varying degrees of severity; multiple handicapping conditions complicated by medical involvement and seizure disorders; emotional disturbance; chronic mental illness with some individuals in forensic mental health centers found to be incompetent to stand trial, while others were serving time in Louisiana juvenile detention centers and adult penal institutions. Because of the nature of the Court's Order, exercised expertise in program development, case management, parent counseling, developmental assessment, behavior analysis, program evaluation, and systems review. Worked closely with Louisiana state officials around systems reform to ensure remedial
actions had a lasting effect; Service Provider and Professional organizations; the advocacy community and the Plaintiffs’ counsel from Children’s Defense Fund and Intervenor-United States Department of Justice. Conducted fact finding that included individual class member status and compliance status, produced reports to the court, issued formal (binding) and informal recommendations, held conferences with the parties, and negotiated stipulated settlement agreements.


Under the professional direction of the Willowbrook Review Panel, a seven member Court appointed panel comprised of nationally recognized experts in the field of developmental disabilities, and under the general direction of the Review Panel Executive Director, provided professional services and consultation to parties involved in this class action suit. Class members totaled 5400 persons of all ages and who were disabled residing at Willowbrook Developmental Center on Staten Island. The consent judgment was signed in 1972, whereas the parties agreed to relocate these individuals into small, homelike community settings and to provide necessary support services including educational, vocational, and health and therapy services. Individual assessment results were the basis for provision of services. Parental involvement, protection of rights and the practice of exercising instrumental due process were closely monitored. Responsibilities included monitoring a Court ordered community placement plan by writing standards that were then applied to assess defendants’ compliance with said order. During this time 2500 of the 5200 class members were living in the community in settings less restrictive than "Willowbrook". These individuals experienced various types of developmental disabilities including mental retardation, cerebral palsy, seizure disorders, multiple handicapping conditions, and visual and hearing impairments due to massive and inhumane research of Rubella, and Hepatitis B. Many individuals also had psychiatric problems including behavior disorders.

Expertise in program evaluation, behavior analysis, individual assessment, program design, policy analysis, systems review, and parent counseling was exercised. Activities included the design of data collection instruments and survey procedures; collection of data, report writing and ongoing technical assistance in matters pertaining to compliance with the Consent Judgment. Recommendations were made to the Court when corrective actions by the defendants were required. I witnessed hundreds of persons with disabilities living successfully in the community.

My work involving Willowbrook class members is cited in David and Sheila Rothmans’ book, Willowbrook Wars: A Decade of Struggle for Social Justice, that traces the history of reforms and litigation at the infamous Willowbrook State School from 1972 to 1983.
8/76 - 10/78  **Behavior Analyst** - Anna Developmental Learning Center, Anna, Illinois.

Anna Developmental Center was an Illinois state operated facility committed to quality services that served 150 individuals who were developmentally disabled. Handicapping conditions of those individuals being served consisted of varying degrees of mental retardation, multiple handicapping conditions, and emotional disturbance.

This program was accredited by the Accreditation Council of Facilities For the Mentally Retarded and Developmentally Disabled and was certified as an Intermediate Care Facility for the Mentally Retarded receiving Title XIX Medicaid Funds. Under the general direction of nationally known behavior specialists, developed and managed a behavior management team that provided assistance in the design and implementation of behavior management programs in this progressive behavioral research oriented facility. Provided technical assistance to parents and community programs in the design and implementation of behavior management programs for individuals of varying handicapping conditions. Participated in the design of apartment living programs and sheltered employment options; and worked closely with psychopharmacologists and nutritionists in a project to reduce the use of certain psychotropic and behavior modifying drugs.

1974-1977  Development Assistant of the Anna Behavioral Profile, a system to assess adaptive behavior and plan supports and services based on assessment results. Anna, Illinois.

8/76 - 10/76  **Team Leader** - Anna Developmental Learning Center, Anna, Illinois. Under the direction of Anna Developmental Learning Center's living units coordinator, and as an experienced professional, supervised and directed 15 staff, engaged in activities of applying the principles and techniques of behavioral sciences to the observation, evaluation, development of procedures and care of 30 young adults who are severely and profoundly retarded.

5/76 - 8/76  **Program Coordinator** - Under general supervision of the Anna Developmental Learning Center's administrator, supervised and coordinated the activities of specialized program service areas, including recreation, education, hearing, speech and religious services. Responsible for the coordination and integration of specialized services into a cohesive program, ensuring cooperation and communication between the various service areas.

2/76 - 5/76  Under the direction of the Anna Developmental Learning Center's living units coordinator, and as an experienced professional, supervised and directed 18 staff, engaged in activities of applying the principles and techniques of behavioral sciences to the observation, evaluation, development of procedures and care of 25 young adults who are mild and moderately retarded young adults.
9/76 - 1/77 Counselor Southern Illinois Clinical Services, Southern Illinois University, Carbondale, Illinois. (Counseling Internship) Sample of cases:

- Acutely, emotionally disturbed 13 year old female, utilizing a cognitive behavioral therapy approach.
- An 8-year-old child with Down Syndrome and her parents using a behavioral approach for weight control.

8/74-5/76 Program Specialist Anna Mental Health and Developmental Center, Anna, Illinois

Responsible for developing social skills and personal care programs for severely and profoundly disabled individuals using applied behavior analysis to measure staff performance and skill development outcomes. Worked closely with Anna Behavior Research Institute nationally recognized researchers in methodology design, data collection and analysis. Toilet training and replacing maladaptive behaviors with new positive behaviors by expanding repertoires of institutionalized adults, was the focus of our work. Eliminating socially unacceptable behaviors provided opportunities for community acceptance.

Worked with chronically mentally ill patients to improve personal hygiene using applied behavior analysis. Measurable outcomes included improvements in the patient’s self esteem, participation in treatment goals, and positive movement toward out patient services.

Worked with acute mentally ill young adults (some also mentally retarded/physically disabled) using applied behavior analysis to teach independent living skills, coping strategies, and biofeedback techniques.

6/74 - 8/74 Educational Leave of Absence: Special Education Department: Southern Illinois University at Carbondale, Illinois, Continuing Education; Eight week European study tour.

I was one of 18 U. S. representatives who visited 50 facilities for person's who are physically and mentally handicapped in nine Western European countries. The "Normalization Principle" by Bank Mikkleson, a parent and pioneer, advocating for equal rights of individuals with intellectual disabilities, was the study's academic focus and emphasis in seminars and written educational materials. Each country's health, education and welfare dignitaries shared educational and social service information such as organizational methods, service distribution structures, types of program delivery systems and accountability measures. Social service, health care and educational programs for individuals with various types of disabilities and their respective support needs were examined. Meetings were held with parent associations, peer and advocacy support groups, professional trade group representatives, and direct support caregivers. We attended a UNESCO conference and shared with participants our professional experiences in the US. Site visits included Montessori schools, public and private community residential programs, and Anthroposophic homes, schools, and villages seen to provide a
positive alternative to traditional forms of institutional care; facilities for individuals with special needs - hospitals, rehabilitation centers, prisons, a Leper colony and Dachau. Upon return to the United States was a member of a panel presentation at United Nations, to exchange information and professional experiences gained from the study tour. Final exam: Essay- Based on what you have learned-How will you, within your profession, effectuate systems change? How will you know if you made a difference?

9/73 - 6/74  
Activity Therapist 1 (Reassignment) Anna Mental Health and Developmental Center, Anna, Illinois

Under general supervision of the Anna developmental learning center's program coordinator, was responsible for meeting the socio-recreational program needs of 50 persons who were developmentally disabled. Ages ranged from 7-13 years on one living unit and 13-40 years of age on another.

8/72 - 9/73  
Activity Therapist 1 Anna Mental Health and Developmental Center, Anna, Illinois.

Responsible for the planning, implementation and evaluation of therapeutic socio/recreational programs for adults who were mentally ill and resided on an admissions unit. Served as a member of a diagnostic treatment team that utilized a multi-disciplinary approach.

8/72 - 11/72  
Health Educator, Southern Illinois Migrant Worker's Council, Mobil Health Clinic, Cobden, Illinois.

Served as a health educator, teaching Mexican-American migrant workers and their families’ basic health care, prenatal and child care routines, cooking skills, and alternative uses to leisure.

9/72 - 6/72  
Program Coordinator, Styrest Nursing Home, Carbondale, Illinois.

Coordinated programs for residents of this facility who were of a geriatric age and/or chronically mentally ill. Assisted in the program development of a 72-bed wing for children who were multi-handicapped and medically involved. This wing served children who were Illinois citizens that were being returned to Illinois from out of state placement. Coordinated the medical team and other disciplines to assure transfer trauma was minimized during relocation to this Illinois facility.

10/71 - 3/72  
Social Skills Trainer, Federal Grant: Anna Mental Health & Developmental Center, Anna, Illinois.

Planned and implemented social skills training and recreational programs for adults who are were severely mentally ill and others who were mentally retarded.
Participated in toilet training programs, token economies, and applied behavior analysis.


Teacher's Aide in a segregated learning disabilities classroom in a public elementary school. Teacher's aide in a special education resource-learning center. Students’ age ranged from 8 months to 10 years. Twenty-four students rotated through this classroom where activities were individually designed based on developmental assessment results. Responsible for motor skill and visual perception assessments and the design of activities to ameliorate problems. Specifically assigned to 3 infants, 2 with Down Syndrome and 2 ten year olds who were mildly handicapped.

**Academic Experience**

2011  Guest Lecturer, Law School, University of South Dakota, Disability Law Class Actions

2011  Adjunct Professor, Department of Education, University of South Dakota: Graduate level: Independent Studies

2010  Guest Lecturer, University of the Virgin Islands Institute for Persons with Developmental Disabilities (DD), Dual Diagnosis: DD and Mental Illness

2007  Adjunct Professor, Department of Education, University of South Dakota: Graduate level: Independent Studies

2002-2004  Adjunct Professor, Department of Education, Dordt College, Sioux Center, Iowa Taught undergraduate level courses: Methods and Strategies for the Instruction of Severely Handicapped Students, Supervised Community Service and Field Experiences-Juvenile Detention Center, Residential Treatment Center, Medicaid Home and Community Based Waiver-supported living and employment and family support (Respite services); Regular and Special Education Class Rooms and public and private Day Care.

1/01-9/01 Adjunct Professor, University of Virgin Islands, St. Thomas and St. Croix, USVI. Project Coordinator - “Full Inclusion”; Teams of teachers and administrators learned strategies for providing support to students and school personnel during integration into regular school activities. Responsibilities included training institutes, teaching, and providing direct support at public schools on all three islands.

2/00-6/00; 9/00-1/01 Adjunct Professor, University of Virgin Islands, St. Thomas and St. Croix, USVI. Taught graduate course in assistive technology for persons with disabilities. Students were full time public employees of the Departments of General and
Special Education, Early Childhood, Vocational Rehabilitation, and Aging. This course was team taught with national consultants and professors from Temple University Institute for Developmental Disabilities. Supervised field experience and provided government agencies technical assistance.

1/87-5/89  Professor, Department of Special Education, Central Connecticut State College, New Britain, CT. Taught five (5) semesters graduate and undergraduate level courses: Individualized Instruction for Severely Handicapped Students, Individualized Assessment of Severely Handicapped Students, Educating the Exceptional Learner, and Introduction to Autism.

Consulting Experience

Sioux Center, Iowa, Public School; Positive Behavioral Supports: Special Education Students with Severe Reputations, 2009-2010.


Human Resources Group: Commonwealth of Kentucky, Cabinet for Health & Family Services, Department for Mental Health & Mental Retardation. Risk Management consultant as required by Memorandum of Understanding (MOU) between the United States of America and the Commonwealth and the MOU Strategic Action Plan in the matter of Oakwood Communities. Evaluated quality of services, participated in the review of individual and system risk factors, provided technical assistance in the design and implementation of the Quality Improvement Program and provided management with recommendations to reduce risks. September 2005-March 2006.

Virginia Office Protection and Advocacy. Evaluated quality of services and analyzed risk management activities at a public institution for individuals with developmental disabilities. 2005

Lutheran Social Services of the Virgin Islands. Evaluate quality of services and provide technical assistance and staff training. Programs included services for children and adults with psychiatric issues and/or developmental disabilities. June 2000 - August 2001.

United States Virgin Islands Territorial Government, Department of Human Services-Division of Vocational Rehabilitation. Evaluate challenging clients and provide counselors assistance in the development of appropriate Vocational Rehabilitation Plans. May, 2000-August 2000.


University of the Virgin Islands Affiliated Program for Persons with Disabilities. Conducted workshops for seniors and assistive technology on St. Thomas and St. Croix. May 2000.
Southern Legal Counsel, Gainesville, Florida. Evaluate adequacy of State of Florida Department of Health and Rehabilitative Services (HRS), Psychotropic Medication Regulation For HRS Institutions; Provide guidance towards revisions that conform to contemporary medication management practices and safeguards to protect against harm. The development and implementation of this regulation was developed as remedy to a wrongful death in *LeClair v. Williams*, Case No. 81-0008 MMP, United District Court, Northern District of Florida, Gainesville District. October 1999-2001.

Southern Legal Counsel, Gainesville, Florida. Evaluate conditions at unit at Northeast Florida State Hospital for persons with dual diagnosis of mental illness and mental retardation; Evaluate needs of individual class members of *Armstead vs. Coler* (Case No. 84-96-CIV-J-12, United District Court of Florida, Jacksonville Division) and make recommendations to the team; Monitor placement planning process and evaluate adequacy of community placement within 6 months of discharge. October 1999 - Present.

Florida Advocacy Center Inc., Fort Lauderdale, Florida. Evaluated quality of community placements funded by the Medicaid Community Based Waiver. September-1999.


Seven (7) attorneys of the New Mexico Trial Lawyers Association who represented six (6) plaintiffs in *Botello v. Las Vegas State Hospital*. Conducted evaluations and worked with facility teams to develop recommendations and plans for community placement. 1994 until settlement in 1996.

Center for Public Representation. Participant in a planning workshop to conduct a review of the effects of the 1976 Brewster (Northampton, Mass. State Hospital) v. Dukakis lawsuit and develop strategies for enhancing services and supports to persons with disabilities the next decade, November, 1996.

Center of Public Representation. Evaluated conditions at Dever State School and select community residences; and evaluated the community placement planning process, December 1995.

Massachusetts Attorney General, Special Counsel to the Governor and Commissioner of Mental Retardation Services. Evaluated Wrentham and Fernald institutions for persons with developmental disabilities; Discussed solutions to resolve protracted litigation. November 1995.

Wyoming Advocacy Inc. Evaluated the state’s community program, the de- institutionalization process and the conditions at the only public institution. Provided guidance in the development of a Quality Assurance Implementation Group as a remedy for the Court’s disengagement in the matter of Lander Training Center, August-October 1994.

Center of Public Representation. Analyzed consumer injuries at a Massachusetts public institution. The analysis and recommendations about quality assurance safeguards was shared with the facility administrator. Many of the recommendations were implemented. 1993.

North Dakota Association of Retarded Citizens. Evaluated North Dakota’s community programs, the State’s quality management system and conditions at the only public institution. 1992-1993. Provided testimony about compliance status with the Court’s orders.

Utah Protection & Advocacy Center. Evaluated facility quality assurance system and placement planning procedures at a public institution; Evaluated draft consent decree for de-institutionalization in the matter of *Pannet v. Angus*. 1993.


Texas Department of Mental Health and Mental Retardation Task Force in the design of a Quality Assurance system to include abuse/neglect reporting and investigation, citizen monitoring, case management, community options/owning own homes, choice making/self advocacy, and safeguards against harm. August 1992.

New Mexico Protection and Advocacy Inc. Monitored 90 class members of *Jackson v. Ft Stanton* who were at significant risk of harm due to complex medical needs and/or behavior difficulties. Analyzed monthly progress reports and provided interdisciplinary teams technical assistance in program design. These individuals resided at two institutions-Los Lunas State School & Hospital and Ft Stanton State School & Hospital. 1991-1992.

Maryland Disability Law Center. Accompanied a representative from the governor’s office and state department of health officials on a tour of Great Oaks Developmental Center for the purpose of discussing concerns about facility conditions, placement planning practices, and community program alternatives. Settlement May 1992.


Maryland Disability Law Center. Evaluated the Maryland developmental disability services quality assurance system. Visited community programs and public institutions and met with health department inspectors and officials and representatives from the governor’s office and the office of the attorney general. Developed a plan of correction that became the foundation of a settlement agreement. Fall of 1991.
Alabama Protection & Advocacy for the Mentally Ill. Evaluated the quality of conditions at one facility and the system wide discharge planning process in the matter of Wyatt vs. King. September 1991.

Court monitor’s office in Arnold vs. Maricopa County, Arizona. Reviewed adequacy of defendant’s quality assurance plan for services for persons with mental illness and provided comments. August 1991.

Texas Advocacy Inc. in Lelsz vs. Kavanagh. Evaluated the adequacy of habilitation for nine (9) individuals who are developmentally disabled and who have mental health needs. Settled with appropriate placement and mental health services. June 1991.


Connecticut Department of Mental Retardation. Design of a comprehensive quality assurance system, August-December 1986.

Connecticut Department of Mental Retardation. Participated in the development of a comprehensive community based system to include: residential programs, integrated day programs, community support services, placement procedures, case management and quality assurance. September 1984.

Connecticut Protection and Advocacy "Adequacy of Evaluation methods used to determine types of adaptive equipment and habilitation and training programs needed by individuals with complex medical and behavioral needs." December, January 1983.


Lorraine Manor Nursing Home Management -Special evaluation of Lorraine Manor Nursing Home and recommendations to improve services for persons who are mentally retarded and have complex medical needs, Hartford Connecticut 1980.


Parent of Down Syndrome child to provide developmental assessment and consultative services to child (7 years old) in designing his Individual Education Plan to reflect his needs as required by Education Law P.L. 94-142. Hartford, Connecticut 1979.


**Special Master and Court Monitor (• indicates trial or deposition testimony)**

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<tr>
<th>Date</th>
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<tr>
<td>•December, 1993</td>
<td>Special Master <em>Halderman et al. v. Pennhurst et al.</em>, Civil Action No. 74-</td>
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<td>compliance with community placement requirements and made</td>
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<td>recommendations to the Court.</td>
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<td>•November 1990-</td>
<td>Special Master in <em>Halderman v. Pennhurst</em> in response to a contempt</td>
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<td>May 1991</td>
<td>motion filed by plaintiffs. After a trial the defendants (City of Philadelphia</td>
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<td>&amp; Commonwealth of Pennsylvania) were found to be in contempt of the</td>
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<td>1978 Settlement Agreement.</td>
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<td>January 1987</td>
<td>No. 74-1365, United States District Court, Eastern District of Louisiana.</td>
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**Expert To The Court**

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<tr>
<td>December 2007 -</td>
<td><em>Jackson et. al. vs. Fort Stanton et. al.</em>, Civil Action No. 87-0839, United</td>
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<td>Present</td>
<td>States District Court for District of New Mexico, Honorable James P. Parker.</td>
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<td>District Court, Northern District of Texas, Dallas Division, Honorable</td>
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<td>Barefoot Sanders.</td>
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• April 1988 - October 1988  
  *Halderman et al. v. Pennhurst State School and Hospital et al.*, Civil Action No. 74-1345, U. S. District Court, Eastern District of Pennsylvania. (Compliance review in community settings.) Honorable Raymond Broderick

1979-1980  

• December 1982- January 1983  
*Hilburn et al v. Commissioner, Connecticut Department of Income Maintenance (Mahr).* U. S. District Court, Connecticut "Appointment of a Special Master and design of an evaluation process to determine types of adaptive equipment and training programs for individuals with complex medical and behavioral needs."

• September 1980- May 1991  
*B.H. et al., v. Johnson*, Illinois Department of Children and Family Services, Civil Action No. 88-C-5599, United States District Court, Northern District of Illinois, Eastern Division.

1978-1980  
*NYARC et. al., v. Carey*, United States District Court, Eastern District of New York. Honorable John Bartells

**Consultant United States Department of Justice**

2010  
United States v. Georgia, Case No. 1:-10-CV-249-CAP (January 28, 2010), Prepared Declaration for Hearing; Landmark Settlement to resolve the unlawful segregation of individuals with mental illness and or developmental disabilities in state-run psychiatric hospitals. In a compromise, Georgia agreed to development of additional DD community services and offer a range of community services for 9,000 people with serious mental illnesses.

2010  
United States v. Georgia, Case No. 1:-10-CV-249-CAP (January 28, 2010), Assessed State’s efforts to comply with the American’s Disability Act with regard to persons residing in 5 State Hospitals (ADA); evaluated Georgia’s community capacity to accommodate persons from State Hospitals; evaluated sample of Medicaid Home and Community Based Waiver funded community homes; met with individuals living successfully in homes of their own, and families in support of community integration.

2010  
United States v. Georgia, Case No. 1:-10-CV-249-CAP (January 28, 2010), Assessed State’s efforts to comply with the American’s Disability Act with regard to persons residing in 5 State Hospitals (ADA); focusing on health, safety and welfare; Federal investigation began after more than 100 suspicious deaths of patients in state mental hospitals were documented over a five-year period.

2010  
with Department of Justice and Bazelon Center for Mental Health Law attorney’s to review evaluation findings and recommendations.

2010 United States v. Georgia, Case No. 1:-9-CV-119-CAP (January 15, 2009), monitored defendant’s compliance with the Court Adopted Settlement Agreement focusing on appropriate community integration, discharge planning, quality community services; Georgia’s community capacity;

2010 Expert consultant in the development of quality assurance systems and risk management, standards of care: treatment planning and service delivery, behavior support services, discharge planning and community integration in USDOJ cases under investigation.

October 2009 United States v. Georgia, Case No. 1:-9-CV-119-CAP (January 15, 2009), Evaluated compliance with Global Settlement Agreement at Southeast Regional Hospital-a facility for individuals with developmental disabilities and a psychiatric facility in Thomasville, Georgia; school age and adults

August 2009 United States v. Georgia, Case No. 1:-9-CV-119-CAP (January 15, 2009), Evaluated compliance with Global Settlement Agreement at Greater Atlanta Regional Hospital-a facility for individuals with developmental disabilities and a psychiatric facility in Atlanta, Georgia; adolescents and adults

May 2009 United States v. Georgia, Case No. 1:-9-CV-119-CAP (January 15, 2009), Evaluated compliance with Georgia Global Settlement Agreement at East Central Regional Hospital-a facility for individuals with developmental disabilities (Gracewood) and a psychiatric facility in Augusta, Georgia school age and adults

March 2009 Working draft: Texas Global Settlement Agreement involving 13 Texas facilities; Provided consultation: Requisites of Quality and Risk Management Systems-Facility and Statewide

October 2008 Evaluated conditions and discharge planning at Rosewood Developmental Center, Owings Mills, Maryland, a facility for adults with developmental disabilities.

June 2005 Evaluated conditions and discharge planning at Lubbock, Texas Developmental Center, a facility for 344 individuals (school age and adults) with developmental disabilities.

June 2000-2007 Evaluated the effectiveness of discharge planning and quality of community placement for a select number of former residents of Fort Wayne State Developmental Center and at Muscatatuck State Developmental Center in Indiana. Also provided the Indiana Family and Social Services Administration with recommendations for improvement of the Indiana community service system for Indiana citizens with developmental disabilities. Conducted numerous facility and community tours (average 2 tours per year, visiting approximately 20 individuals each year in their community residence and day program), monitoring
implementation of the Strategic Plan attached to the United States and Indiana Settlement Agreement.

January 1999-2002
Evaluated conditions and discharge planning at Rainier State Developmental Center (480 person institution) and at Francis Haddon Morgan Center (55 persons) in Washington. Participated in discussions with Washington officials and representatives of USDOJ regarding corrective actions.

October 1998-March 2007
Evaluated service quality and discharge planning at Fort Wayne State Developmental Center (437 person institution) and at Muscatatuck State Developmental Center (383 persons) in Indiana. The Indiana Family and Social Services Administration and USDOJ agreed to have me complete the evaluations and make recommendations for improvements. MSD closed March 2004 and FWSDC closed June 2007. Conducted numerous tours of the facilities and provided consultation in methods to improve quality.

July 1998-2000
Evaluated the effectiveness of discharge planning and quality of community placement for a select number of former residents of New Castle State Developmental Center (NCSDC), New Castle, Indiana; also provided the Indiana Family and Social Services Administration with recommendations for improvement of the Indiana community service system for Indiana citizens with developmental disabilities.

May 1998
Evaluated Indiana’s implementation of a community placement plan involving 165 persons residing at NCSDC and also assessed the quality of services for those individuals remaining at NCSDC.

October 1997.
Conducted an evaluation of (NCSDC), a 165-bed facility for persons with developmental disabilities.

March 1995.
Participated in negotiations between the parties and helped draft a stipulated agreement in the matter of United States of America v. State of Oregon regarding protection from harm of individuals residing at Fairview Training Center, a public institution.

August 1994
Evaluated service quality in a public ICFMR (Fairview Training Center) to determine compliance in the manner of United States of America v. State of Oregon. A report and recommendations for protection from harm became the basis for additional remedy in this protracted (1986 consent order) litigation.

•June 1994.
Evaluated the adequacy of the defendant’s and the court monitor’s remedial plan to correct constitutional violations in United States of America v. State of Tennessee.
System Reform Expert: Health and Safety, Active Treatment, Discharge Planning, Community Integration and Quality Assurance

• 2006-2009
  *Ligas et al., vs. Maram*, No. 05-4331 Class Action, United States District Court For The Northern District Of Illinois, Eastern County. (Individuals with intellectual and/or developmental disability residing with family, in community congregate settings, or segregated institutions waiting for Medicaid Home/Community Based Waiver (HCBW) funded services. Evaluated needs of a sample of individuals eligible for HCBW services.

• 2005-2009
  *Capitol People First, et al., vs. Department of Developmental Services*, Case No. 2002-0387156, Superior Court of the State of California, Alameda County. (Individuals with intellectual and/or developmental disability residing with family, in community congregate settings, or segregated institutions waiting for Medicaid Home/Community Based Waiver (HCBW) funded services.) Evaluated needs of a sample of individuals eligible for HCBW services; adequacy of California’s planning policies, and resource development. Provided remedial recommendations.

• 2005
  *ARC Connecticut et al., v. O’Meara, 3:01 CV 1871 (JBA)*, United States District Court for District of Connecticut. Fairness Hearing. Provided Court testimony involving an assessment of the fairness of the community services provisions of a proposed settlement agreement.

2003-2004
  *ARC Connecticut et al., v. O’Meara, 3:01 CV 1871 (JBA)*, United States District Court for District of Connecticut. (Individuals with intellectual and/or developmental disability residing with family, in community congregate settings, or segregated institutions waiting for Medicaid Home/Community Based Waiver (HCBW) funded services. Evaluated community service system (residential, case management, health and therapies, employment) capacity.

2004-2006
  *Rolland v. Cellucci, et al.*, Civil Action No. 98-30208-KPN, United States District Court for District of Massachusetts. (Individuals with developmental disabilities residing in nursing facilities, who lived in nursing facilities on or after a date certain or should be screened for admission to nursing facilities pursuant to federal requirements. Individuals with mental retardation/ developmental disabilities in nursing homes are entitled to federally defined active treatment.)

• 1998-July 2000
  *Wolf Prado-Steiman, et. al, vs. Jeb Bush, et. al.*, Case No. 98-64-96-CIV, Ferguson, United States District Court, Southern District of Florida, Fort Lauderdale Division. (20,000+ individuals with developmental disabilities eligible for services funded by Medicaid Home and Community Based Waiver.)

• 1996-2010
  *Messier vs. Southbury Training Center*, Civil Action No. (one institution) Trial testimony: Active Treatment, placement planning, discharge process, case management, community services capacity; Provided Court testimony
Program Services/Standard of Care Expert

- **2010-Present**  

- **2009-2011**  
  Arpino v. Marrakech and DMR, Superior Court of New Haven, Connecticut, Wrongful death of a man with developmental disabilities living in a community home.

- **2007-2008**  
  Cochran v. Progressive Horizons, Inc., Circuit Court, Baltimore County, Maryland, Case No.: 03-C-06-002182 Wrongful death of a man with developmental disabilities living in a community home.

- **2006-2009**  

- **2006-2009**  

- **2005-2007**  
  The Estate of Michael Root by Harriet Crockett v. Secure Care Services LTD, Health Care Alternative Dispute Resolution Office of Maryland. Wrongful
death of a man with developmental disabilities living in a community facility.

•2005-2010  Santaniello v. Sweet et. al., United States District Court, District of Connecticut, No. 3:04CV806 (RNC), Personal injury of woman living in community home.


Program Services/Standard of Care Expert


•2007-2008  Cochran v. Progressive Horizons, Inc., Circuit Court, Baltimore County, Maryland, Case No.: 03-C-06-002182 Wrongful death of a man with developmental disabilities living in a community home.


•2005-2010  Santaniello v. Sweet et. al., United States District Court, District of Connecticut, No. 3:04CV806 (RNC), Personal injury of woman living in community home.


Professional Affiliations

Association For Positive Behavior Support 2007-Present.

International Association of Forensic Nurses (IAFN) 2006-Present.

Association of Qualified Mental Retardation Professional 2005-Present.
American Association on Intellectual and Developmental Disability (AAIDD) formerly (AAMR) 1977 - Present.

The Association for Persons with Severe Handicaps (TASH), 1977 - Present.

National Association of Persons with a Dual Diagnosis (NADD), 1995-Present.

Association for Advancement of Behavior Therapy, 1982 - Present.


Publications


Additional Education

June 2010 Neurologic Care: A Multidisciplinary Approach. NADD
March 2010 Death Investigations; International Forensic Nurse Association
October 2007 Combining Functional Behavioral Assessment and Social-Communication Interventions: Addressing Developmental Disabilities in Autism Spectrum Disorders. NADD
September 2006 Crisis Prevention and Intervention for Adults with Autism: The Team Centers, Inc. Chattanooga, Tennessee. NADD
October 2006 The Medically Fragile Patient: Management of Seizure Disorders, Diagnosis and Treatment of Dysphagia, Characteristics and Management of Digestive Disease: St. Mary’s Hospital and Mayo Clinic, Rochester, MN.
March 2006  New Medicines in the Developmental Disabilities Field. NADD Symposium
November 2005  Dysphagia and Risk Management Training Institute: John Hopkins
December 2003  Inclusive School Renewal: Creating Effective Schools for All Students Symposium. (TASH)
September 2002  Psychiatric Disorders in Children and Adolescents with Mental Retardation and Autism Spectrum Disorders. NADD
July 2001  Pharmacotherapy of Psychiatric Disorders in MR/DD Population, with a Focus on Some Unique Diagnostic and Treatment Challenges, NADD Training Institute.
July 2001  Demystifying Physical Health Causes and Behavioral Health Symptoms. NADD Training Institute, Lancaster, PA.
June 2000  Advanced Directives: An Important Legal, Ethical, and Clinical Issue for People With Severe Developmental Disabilities and Complex Medical Problems. (AAMR)
June 2000  Understanding Swallowing Problems (Dysphagia and Aspiration) in Adults with Mental Retardation. Symposium
May 2000  Reducing Abuse and Use of Restraints, Health Care Financing Administration (HCFA).
May 2000  Approaches to Assuring Optimal Health for Individuals with Disabilities. Symposium
June 1994  “Measuring Quality in a Mental Health System”. Workshop by Court
Monitor in Washington DC Dixon case.

June 1994 Methods used to evaluate and analyze injuries; Implementing a system to measure adverse effects of institutionalization of persons who are developmentally disabled and who have unmet mental health needs. System used in the Thomas S. North Carolina case.

June 1993 “Polypharmacy impact of integration of people with disabilities into community and family practices”, University of Oklahoma.

June 1993 Outcome measures and new standards developed by the National Accreditation Council of Programs for Persons with Developmental Disabilities.

May 1993 The new definition of mental retardation developed by the American Association of Mental Retardation (AAMR).

Other Activities

Iowa local and South Dakota Regional Multi-Cultural Community Meal Volunteer 2010-Present

Senior Companion to Medicaid Elder Waiver recipients, NW Iowa Department of Aging-2010-Present

Community Advisor, Siouxland Palliative Care 2010-Present

Support member for individuals receiving Hospice (Siouxland) care and their caregivers. 2005-Present

Guardian or medical power of attorney, medical case manager and in home caregiver of 3 family elders with variety of diagnoses: Alzheimer’s disease, dementia, physical disabilities, compromised respiratory function, cardiovascular issues, congestive heart failure, and visual impairment/blindness due to macular degeneration. Support and accommodations with supplemental services from Medicaid Elder Waiver, Assisted Living, Palliative and Hospice Care to maintain quality of life while staying in own home. 2001-2010

Virgin Islands Medicaid Reform Task Force Member. 1999-2001

In February, 1994 two colleagues, a doctorate of social work and family practice and a school nurse, and I developed a training program for teachers and parents regarding alternatives to “Hitting, Spanking, Shaking”. This program has been provided to schools and churches in the Virgin Islands.

I was a founding member of the St. John Safety Zone and the Virgin Islands Child Abuse and Neglect Task Force and continued to be active in victim counseling and domestic violence prevention activities from September, 1992-November 2001. I co-authored the V.I. statue defining child abuse and reporting requirements.

I served as a member of the Virgin Island Governor's Council for Maternal and Child Health Care and assisted the Virgin Islands Health Department develop the assessment strategy and analyze the results for the 1996 - 2000 V.I. Health Care Plan for children with special needs. This plan was completed as required by a grant from the U. S. Department of Health and Human Services.
I volunteered as team facilitator of the St. John public elementary and middle school Improvement Plan. This plan was a community effort to implement “Developing Capable People” a values training curriculum.

I was a trained National Red Cross mental health counselor and volunteer of the V.I. Red Cross and V.I. Territory Emergency Management Agency. (VITEMA)


I served as a member of the Advisory Board for Louisiana State University, School of Allied Health, Department of Rehabilitation Counseling, and the Community Living Institute. June 1984-1986.


In 1976 I developed a training procedure to increase social interaction and community learning skills with moderate and severely retarded adults. Diagnosis ranged from seizure disorders, I Klienfelder's Syndrome, Down's Syndrome and serious Cultural Familial Deprivation.
Appendix B
July 24, 2012

Susan Kas
Disability Rights Washington
315 Fifth Avenue, Suite 850
Seattle, Washington 98104

Dear Ms. Kas;

Please find enclosed my initial report on the review of investigations of abuse, neglect, and exploitation, as well as other serious complaints related to Division of Developmental Disabilities’ (DDD) Supported Living Program in Washington State. As we have discussed, I do plan to offer a supplemental report that will offer commentary primarily on the State’s submittal of late documents (May 2012) pertaining to 35 complaints for which no investigation had been completed as of February 12, 2012.1

Background
In accordance with an Expert Consultant Agreement (6/17/2011), I was asked to: “[r]eview necessary records, documents, and information to assess the Washington’s Department of Social and Health Services’ (DSHS) implementation of its Quality Management Strategy (QMS) for its Home and Community Based Services (HCBS) waiver program and its provision of HCBS waiver services to waiver participants.” I completed these activities and had several conference calls with you and other attorneys from Disability Rights Washington and Amy Crewdson of Columbia Legal Services to discuss my observations and the operations of the DSHS’ receipt and investigations of complaints and allegations of abuse and neglect related to clients of its Home and Community-Based Waiver (HCBW) program for persons with intellectual disabilities.

Subsequently, on 3/20/2012, I signed a Testifying Expert Agreement, which asked that I “review necessary records, documents, and information to assess DSHS’ implementation of its QMS to identify, address, and prevent instances of abuse or neglect of Boyle class members receiving [HCBS] supported living services.”

The latter agreement required a number of specific review activities, which I have now completed.

1 It is my understanding that some but not all of these complaints were subsequently investigated between February 12, 2012 and May 15, 2012.
1. Review all DSHS investigation and intake records for incidents involving potential abuse or neglect of Boyle class members participating in the supported living program reported to DSHS for the period June 1, 2011 – August 31, 2011 that were assigned a 2- or 10-working day priority.

2. Review of a sample of all intakes for incidents involving potential abuse or neglect of Boyle class members participating in the supported living program reported to DSHS between June 1, 2011 and August 31, 2011 that were assigned a 20- or 45-day working priority.

3. Review of all current policies and protocols utilized by DSHS for intakes and investigations of incidents involving potential abuse or neglect of Boyle class members participating in the supported living program.

4. Review of all information provided by Disability Rights Washington regarding DSHS’ investigatory resources and capacity to address these incidents.

The agreement specifically asked that I offer expert opinion as to whether DSHS’ investigations were adequate to identify, address, and prevent instances of abuse or neglect and whether DSHS has sufficient policies and resources to address the volume of reported incidents.

My Credentials

As you know, I have considerable experience in reviewing and evaluating states’ incident reporting and investigation systems for allegations of abuse and neglect. (See my curriculum vitae in Attachment D.) I have served as an expert consultant reviewing these systems in Connecticut, Florida, Hawaii, Louisiana, New Mexico, Ohio, Oregon, Tennessee, and Texas. In performing these reviews, I have worked both as a consultant to plaintiffs in various litigation and class action matters and as consultants to state governments (Hawaii, Ohio, Oregon, and Tennessee). I have also been certified as a court expert on these matters by federal district courts in Connecticut, Texas, and Tennessee.

In addition to these activities, I published what has come to be known as seminal article on the design and effective operations of abuse and neglect reporting and investigation systems. (“From Paper Tigers to Consumer-Centered Quality Assurance Tools: Reforming Incident Reporting Systems,” Nancy K. Ray, Mental Retardation, vol. 33, no. 4, August 1995). In this article, I lay out a practical framework for program administrators seeking to improve the effectiveness of their incident reporting and investigation procedures and practices. The article identifies specific performance indicators for effective systems, including: (i) consumer centeredness, (ii) accountable reporting, (iii) thorough fact finding and investigations, (iv) prompt identification and implementation of corrective action, (v) fairness, and (vi) cost-
effectiveness. This framework has been relied upon by several states, including Ohio, Tennessee, Oregon, and Pennsylvania, in evaluating and improving their abuse and neglect incident reporting and investigation systems.

It is also important to reference that effective abuse and neglect incident reporting and investigation systems are widely acknowledged to be a foundational element of all health and human services programs. Federal and state legislation and rules and regulations require these systems for virtually all health and human services entities from state institutions to hospitals to nursing homes to group homes to day care centers.

The Centers for Medicare and Medicaid has been especially stringent in its requirements for these systems for home and community-based waiver programs, like the Home and Community-Based Waiver Supported Living Program in Washington State. The failure of states to assure adequate systems in this area has, in fact, led the Centers of Medicare and Medicaid to place moratoriums on the expansion of these programs in several states and to threaten states with the termination of Medicaid funding for these programs altogether.

Government’s actions in this area reflect the public sentiment, as reflected in ongoing public media reports, that community programs supporting its vulnerable citizens with intellectual and mental disabilities must fundamentally assure that these service recipients are protected from abuse and neglect. Notably, although many states have had difficulties meeting the standards of the Centers of Medicare and Medicaid for effective abuse and neglect incident reporting and investigation systems, with concerted efforts, states have been able to find practical and cost effective approaches to strengthen their systems and meet these standards. For example, although both Ohio and Tennessee were faced with severe sanctions by the Centers of Medicare and Medicaid with regard to these systems for their home and community-based waiver programs, with sustained efforts, both are now recognized to have what are considered model abuse and neglect incident reporting and investigation systems.

Methods

In conducting this review, I have reviewed the following policies and documents:

(i) Operational Procedure for Complaint Resolution Unit (CRU) Complaint/Incident Referral Processing in Field Offices, DSHS, (2/2007);

(ii) Residential Care Services (RCS) Operational Principles and Procedures for Certified Community Residential Service (CRS) Agencies [for] Complaint/Incident Resolution, DSHS, (7/2011);

(iii) Protection from Abuse: Mandatory DSHS Reporting, Policy 5.13, Division of Developmental Disabilities, DSHS, September 2011;
(iv) Residential Care Services, Operational Principles and Procedures for the Resident and Client Protection Program (RCPP), Investigation of Individuals, DSHS, July 2011;

(v) RCS Complaint Priorities (12/30/2003);

(vi) Department of Social and Health Services, Division of Developmental Disabilities, Incident Reporting, Policy #12.01 (February 2012);


(viii) Engrossed Substitute House Bill 1277, 62nd Legislature, 2011 1st Special Session (Passed the House on 5/2/2011 and passed the Senate on 5/10/2011);

(ix) “Improving Washington’s Response to Abuse & Neglect, Analysis & Recommendations,” Disability Rights Washington, April 2008; and

(x) Letter from Robert McClintock, Quality Assurance Administrator, Residential Care Services Division, DSHS to Regan Bailey, Disabilities Rights Washington and Amy Crewdson, Columbia Legal Services, 7/22/2011.

In addition to the review of the above documents, I have reviewed a subset of complaint reports for the 233 complaints filed with regard to the Waiver-funded supported living program during the period June – August 2011. I was told that this subset of complaints was comprised of all of the complaints received during the three-month period that had been assigned a two- and ten-day investigation initiation priority by DSHS. These complaints were reportedly the most serious of the complaints received for that period.

The files on the 233 complaints included all investigations and investigation working papers for these complaints conducted by DSHS’ RCS’ Division as of February 12, 2012. In addition, I was sent closing documents, investigations, and associated documents related to 33 of the above complaints conducted by the Resident and Client Protection Program (RCPP), which is a sub-division of the RCS. This set of documents included investigations and associated documents related to the complaints in the original RCS data file, as well as nine additional complaints not in the above original file. All of the latter complaints related to complaints assigned 20- or 45-day investigation initiation priority ratings.

In reviewing the above complaint files, I created Excel spreadsheets to track various information, including the investigation initiation priority ratings of the complaint, the dates the complaints were filed, the dates investigations were initiated and completed, the subject(s) of
the complaints, the nature of the complaints, and a summary of the investigation findings. I also classified the complaints by type of complaint and noted the limitations of the completed investigations.

Through this review process, I discovered that the 233 filed complaints included a number of complaints (usually filed by different reporters) that referenced similar matters and that were apparently handled by DSHS as single cases. Although usually not explicitly referenced in their case files, it was subsequently determined that the 233 complaints were associated with 162 “unique” cases.

To ensure that limitations in the handling of the similar complaints were not “over-counted” in my analysis, I used the 162 “unique” cases as my reference point. For example, if I located no investigation for a particular complaint or complaints, but found an investigation linked to a complaint referencing the same or similar matter, I considered that the related complaints were also investigated. Similarly, in calculating the days lapsed between the complaint referral and the initiation and completion of the investigation of associated complaints, I relied on the shortest time lapse for all associated complaints.

Further review of the 162 “unique” cases indicated that they were associated with many different types of complaints and that 18 of the cases clearly referenced two different types of complaints. The vast majority of the cases (117 or 72%), however, were associated with complaints of neglect (by caregivers), client-to-client assaults/abuse, physical abuse (by caregivers), verbal abuse (by caregivers), and sexual abuse (by caregivers). Less frequently referenced complaints related to mistreatment/psychological abuse (n = 9), client self-injury/suicide attempts (n = 7), financial exploitation (n = 7), and client sexual activity with another client (n = 6). Complaints related to client-to-staff aggression (n = 4), deaths (n = 3), substance abuse (n = 3), and medication errors (n = 1) were even less common.

Major Findings

My review found that DSHS does not adequately identify, address, and prevent instances of abuse or neglect and other harmful situations for clients residing in the Waiver-funded supported living program. The review also indicated that the DSHS policy framework governing its response to complaints and allegations of abuse and neglect in the Waiver-funded supported living program is critically compromised.

Certain critical issues, like the supported living provider agencies’ responsibilities to investigate complaints, the requirements for these investigations, and the prerequisite training credentials of their investigators, are not addressed at all by DSHS’ policies. Other procedures prescribed by the policies are routinely not complied with, either because resources to ensure their implementation are not available or supervisory oversight by DSHS is so lax that non-compliance by investigators and their supervisors has become commonplace. For example,
investigations are rarely initiated in accordance with their assigned investigation initiation priority assignments; investigation plans are often not developed and apparently never reviewed/critiqued by supervisors; and supervisory reviews of completed investigations are usually not “completed” for months and the only evidence of supervisor’s critical reviews of these reports is a signature and date.

Still other prescribed procedures and practices are inherently faulty and result inevitably in excessive delays in the initiation and completion of investigations and unaccountable records of investigator’s interviews with witnesses and victims. Most fundamentally, DSHS’ practices do not ensure accountability that all complaints and allegations of abuse and neglect are investigated. In this data sample of the 162 most serious cases received in the period June – August 2011, only 9 of the cases (5%) were formally investigated with regard to the employee abuse, neglect or other misconduct alleged.

More specific observations and findings of the review are listed below.

D There is too little accountability that all filed complaints, especially similar or duplicate complaints, will be addressed. The reviewed data base of 233 complaints included 71 duplicate or similar complaints. As noted above, it was ultimately determined that there were 162 “unique” cases in the data base. DSHS, however, has no formal system for ensuring that the duplicate or similar complaints are tagged together and that investigation reports reference all complaint calls on similar situations. Additionally, there is no assurance that all complaints referenced in the various similar complaint calls are addressed in DSHS’ investigations.

D DSHS has not taken adequate actions to ensure that complaints are reported in a timely manner. Only 78 or 48% of the filed complaints were called in within one or two days of their occurrence. An additional five of the cases (3%) were filed within three to five days of their occurrence and seven cases (4%) were filed with six to ten days of their occurrence. An additional 42 of the 162 cases (26%) were reported as “ongoing” concerns or complaints of misconduct that had been occurring for weeks or months prior to the filing of the report. And, 24 of the 162 cases or 15% were filed with an “unknown” date of the incident. It was not possible to determine if these cases were or were not filed in a timely manner. Significantly, DSHS investigations of these complaints rarely referenced or cited provider agencies or their staff members for late reporting. [See Table 2 and Chart A.]

D DSHS’ system for prioritizing the initiation of investigations is inherently flawed, as it sets goals for the vast majority of investigations of complaints/allegations not to start until 10 – 45 days after they are reported. During the review period, only approximately 5% or 14 of the filed complaints were assigned two-day investigation initiation priority.
More than half (55% or 147) were assigned a ten-day investigation initiation priority and 40% or 106 were assigned a 20- to 45-day investigation initiation priority. [See Table 3.]

These delays fundamentally compromise investigations. The memories of disabled clients, as well as witnesses, of what happened are diminished; physical evidence may be lost; the scene of the incident is likely no longer intact; witnesses may go missing; and injuries to the victim may have healed, etc. Such delays also allow for those involved in the incident to re-construct less than truthful accounts that better serve their self-interests.

D  **DSHS’ assignment of investigation initiation priorities is not always consistent or reliable.** Often duplicate or similar complaints related to the same situation were assigned different investigation priorities. This was most evident in the review of duplicate or similar complaints where one or more had been assigned a two-day investigation initiation priority. Seven (7) of these 14 cases were associated with at least two duplicate or similar complaints. The review found that duplicate/similar complaints associated with five of these seven cases had been assigned different investigation initiation priorities, ranging from 10 – to 20-day investigation start dates. [See Chart B.]

D  **Although the investigations of the small number of cases (14 of the 162) assigned a two-day investigation initiation date were usually (79%) initiated within two days of the report, this was not usually the case for the ten-day investigation initiation priority cases.** Only one-fifth (20%) of the investigations of the latter cases were initiated within 10 days. Thirty-five (35) or 24% of these investigations were not started until three or more weeks after the report was filed, including 17 or 11% that were not started until more than eight weeks after the report was filed. Notably, for an additional 33 (22%) of the 10-day investigation initiation priority cases, there was no evidence that an investigation had been initiated at all. [See Table 4 & Table 5 and Chart C.]

D  **In part due to the delayed start dates of investigations, the completion of investigations for most of the cases in the data base was also critically delayed.** The review found that only 44% (72 of the 162) were completed within 30 days of the date of the report, which is the standard relied upon by most states. The analysis showed that 17 additional cases (11%) were completed in 31 – 60 days, but that a significant 73 of the cases (45%) were not completed within 60 days, including 27 (17%) that were not completed until 91 – 199 days after the complaint was filed and 33 (20%) for which no investigation report at all was found in the file. Notably, especially in view of its very untimely investigation performance, DSHS has also failed to establish any benchmark goal for the timeframe for the completion of investigations. [See Table 6 and Chart D & E.]
D The review also found that DSHS’ supervisory oversight of complaint investigators is fundamentally absent much of the time. This observation was evident most apparently in the significant percentage of investigations that were not started on time and/or that were not completed within a reasonable timeframe (or not completed at all). Additionally, however, I found little evidence that Field Managers who are required by RCS procedures to review investigation reports (and related documents) were complying with this assignment in an adequate manner.

The analysis found that only 26 of the 126 (21%) completed investigations had been signed off by Field Managers as reviewed within seven days of the date that investigators documented they completed their investigations. An additional 29 (23%) of the completed investigations were signed off as reviewed by Field Managers within 8 – 30 days of their completion.

More than half of the completed investigations (71 or 56%), however, were not reviewed and signed off by Field Managers until more than a month after they were completed, including 55 or 43% that were not reviewed and signed off by Field Managers until 91 – 211 days after they were completed. (For an additional three cases, there was no documentation of a supervisory Field Manager review in the file.) [See Table 7.]

D In addition to the above timeliness concerns, the review of completed investigations also surfaced a number of systemic substantive concerns with the manner in which the investigations were conducted and investigation summaries were prepared.

Most evidently, the RCS investigators do not write up complete investigation reports. Interviews, even with key witnesses and the alleged victim, were not formally transcribed and summarized. The investigators also do not prepare a formal summary analysis of the investigative findings. In many files, there was also not a complete list of the individuals interviewed.

Complaint files would usually, although not always, include several pages of the investigator’s handwritten very draft and apparently contemporaneous notes. These were scanty notes of interviews, observations, etc. Depending on the investigator, the notes were more or less legible, organized, complete, and understandable to a third party. Although a number of documents pertinent to the client victim and/or client perpetrator were also attached to most cases, the significance of these documents was usually not referenced in the investigation report.

The only official investigation report in the RCS investigation case file was a summary investigative report that rarely exceeded 250–300 words. Most often, half of this report described the involved client and his/her housemate, where they lived, and their level of
staff supervision. The remainder of the report would summarily list the determination, with very little substantiating support. [See Chart F & Attachment C.]

D RCS investigation summaries also often failed to include references to findings pertinent to all complaints raised. It was unclear in these investigation summaries if the unreferenced complaints had been overlooked or if the investigator simply determined that they were so lacking in merit that they did not warrant being mentioned in the summaries. [See Chart G.]

D Another unusual feature of the RCS investigation summaries is that they often did not reference findings pertinent to the allegations of abuse, neglect, mistreatment, and exploitation referenced in the initial complaint(s). In other cases, investigation summaries would reference these allegations and findings regarding their merit, but then conclude that the no provider practice deficiency was identified.

The reports most often indicated that provider agency culpability was not cited because the provider had policies that proscribed the substantiated employee misconduct and the staff members involved had been trained in these expectations. In other words, RCS investigators typically did not cite the provider agency for the faults or misconduct of its employees. In my experience, this is an unusual practice, as employers are usually held culpable for their employee practices.

It also became evident that RCS investigators were conservative in issuing “failed provider practice citations.” In total, RCS investigators substantiated supported living provider agencies for only 27 of the 162 cases (17%) in the data file. I saw repeated evidence that provider agencies routinely escaped a “failed provider practice citation” in circumstances where provider agencies’ practices were clearly faulty. [See Chart H.]

D I later learned from Disability Rights Washington that this was the “official” DSHS practice and that RCS investigators had been instructed not to investigate particular employee abuse, neglect, or misconduct, but only “provider practice” which most often entailed only a review of written policies and procedures and documentation of staff training. I learned that DSHS had determined that a separate group of State investigators assigned to its RCPP Unit, a sub-unit of the RCS, took primary responsibility for assuring that employee (as opposed to provider agency) accountability for abuse, neglect, exploitation, or other serious misconduct in DDD’s Waiver funded supported living homes, as well as other State-funded residential settings. Thus, I asked Disability Rights Washington to send me all RCPP investigations of complaints assigned a two-day or ten-day investigation initiation priority for the same period (June – August 2011) for which I received the RCS investigations.
D The received RCPP file included investigations of only 24 of the 162 cases (15%) in the original database file. Based on the documents received, the RCPP reviewed the documents of 15 of these cases and determined based on the records (apparently received directly from RCS) to “close” the cases. There was no documentation of any RCPP investigation of any of these cases. In a number of these cases, however, the records indicated that employee abuse, neglect, exploitation, or other serious misconduct was confirmed either by the provider agency investigation or RCS. Only 9 of the 24 cases referenced in the RCPP files were actually referred for investigation by the RCPP and of these cases, two were substantiated. [See Table 8 and Chart H.]

D It was notable that investigation reports of the few cases actually investigated by the RCPP were considerably better documented than those of the RCS, with detailed summaries of interviews and the analysis of investigative findings. I received no information to clarify why the RCS and RCPP investigations had apparently such different standards for the documentation of their findings and final reports.

D Overall, the RCPP was involved in very few cases (15% of the 162 “unique” cases in the database). In most cases involving alleged abuse, neglect, exploitation or other serious staff misconduct, employees (as well as provider agencies) escaped State scrutiny/investigation.

D The State’s failure to investigate and make formal substantiation findings of employee abuse, neglect, exploitation, or other serious staff misconduct is significant, as without this formal determination, the employee (notwithstanding his/her substantiation in a provider agency investigation or a report of confirmation of the complaint in a RCS investigation) would not be subject to placement on the State Register of employees substantiated for abuse, neglect, exploitation, or other misconduct. Although these employees (per reports in the case files) were often terminated or otherwise disciplined by their employer, they would be able to obtain employment from another supported living or vulnerable person residential provider without detection of their history.

D In addition to the above systemic concerns, there was also evidence that investigations of certain types of allegations and complaints were particularly limited.

- Investigations of allegations of client-to-client assaults were usually delayed in both initiation and completion for weeks or months. There was also usually limited information in the file as to how victims of these assaults/abuse were protected during

---

2 The RCPP files also included nine additional cases related to complaints filed in the June – August 2011 period, but all of these cases were not in the original database, as they had been assigned priority investigation initiation statuses of 20-days, 45-days, or Quality Review.

3 I was also told that Adult Protective Services had responsibility for investigating allegations of abuse and neglect, but I received no reports of its investigations.
this interlude. In most cases, however, documentation did indicate that victims continued to live with their assailant throughout the period.

- Investigations of reports of client injuries of unknown origin were usually so delayed that by the time the RCS or RCPP investigator arrived on the scene, the injuries had healed and no one, not staff or the client or his/her housemates, were able to reconstruct the events that may have led to the injury. Investigators were thereby restricted to the review of record documentation, which typically provided no insight which was understandable in view of the initial report of the injury as being of unknown origin. Additionally, the investigation summary reports of these reports most typically failed to provide a full description of the injuries as recorded in records reviewed or staff witnesses.

- Reports of client-to-client sexual assaults were also sometimes not fully investigated. In particular, the capacity of the clients to consent to sexual activity, with awareness of its risks and safe sex practices, was usually not fully assessed. The latter was especially significant as most of the individuals involved in these incidents in the data file were enrolled in the State’s special Community Protection Waiver program, due to their histories of inappropriate sexual behavior and, in some cases, criminal histories as sexual offenders.

As reflected in the above findings, the DSHS system for handling and investigating complaints and allegations of abuse and neglect is not adequate. It fails to ensure that all complaints/allegations are investigated and most investigations are initiated and completed far too long after the report is received by DSHS. Investigation reports also provide an insufficient record of the investigator’s findings, analysis of the evidence, and conclusions. In addition, DSHS’ routine “planned ignoring” of allegations of employee abuse and neglect in its investigations is wholly non-compliant with basic expectations of the Centers for Medicare and Medicaid, as well as its own Quality Management Strategy.

For your further information, I have attached several data tables (Attachment A) and several chart summaries of pertinent case examples (Attachment B) that I prepared in conducting my review. Several examples of DSHS summary investigation reports and investigators’ handwritten notes are presented in Attachment C. My curriculum vitae is included in Attachment D.

Sincerely,

[Signature]

Nancy K. Ray, Ed.D.
President
NKR & Associates, Inc.

cc: Amy Crewdson
ATTACHMENT A
DATA FINDING TABLES
### Table 1: Types of Complaints Referenced in the 162 “Unique” Cases

**June – August 2011**

<table>
<thead>
<tr>
<th>Complaint Type</th>
<th>Number of Unique Cases</th>
<th>Percent of Unique Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neglect</td>
<td>47</td>
<td>29%</td>
</tr>
<tr>
<td>Client-to-Client Assault/Abuse</td>
<td>24</td>
<td>15%</td>
</tr>
<tr>
<td>Injury of Unknown Origin</td>
<td>23</td>
<td>14%</td>
</tr>
<tr>
<td>Physical Abuse</td>
<td>20</td>
<td>12%</td>
</tr>
<tr>
<td>Verbal Abuse</td>
<td>14</td>
<td>9%</td>
</tr>
<tr>
<td>Sexual Abuse</td>
<td>12</td>
<td>7%</td>
</tr>
<tr>
<td>Mistreatment/Psychological Abuse</td>
<td>9</td>
<td>6%</td>
</tr>
<tr>
<td>Suicide Attempt, Self-Injury/Neglect</td>
<td>7</td>
<td>4%</td>
</tr>
<tr>
<td>Exploitation/Personal Funds Mismanagement</td>
<td>7</td>
<td>4%</td>
</tr>
<tr>
<td>Client-to-Client Sex</td>
<td>6</td>
<td>4%</td>
</tr>
<tr>
<td>Client-to-Staff Aggression</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>Unexpected Death</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>Substance Abuse (by Client) Associated with Staff Neglect/Abuse</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>Medication Error</td>
<td>2</td>
<td>1%</td>
</tr>
</tbody>
</table>

---

4 Note: The total number in the table exceeds 162 because some complaints/allegations referenced more than one type of complaint/allegation.
TABLE 2: NUMBER OF DAYS BETWEEN THE INCIDENT’S OCCURRENCE AND ITS INITIAL REPORTING TO THE DSHS COMPLAINT RESOLUTION UNIT (JUNE – AUGUST 2011)

<table>
<thead>
<tr>
<th>Days</th>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 2 Days</td>
<td>78</td>
<td>48%</td>
</tr>
<tr>
<td>3 – 5 Days</td>
<td>5</td>
<td>3%</td>
</tr>
<tr>
<td>6 – 10 Days</td>
<td>7</td>
<td>4%</td>
</tr>
<tr>
<td>More than 10 days</td>
<td>6</td>
<td>4%</td>
</tr>
<tr>
<td>Date of Incident “Ongoing”</td>
<td>42</td>
<td>26%</td>
</tr>
<tr>
<td>Date of Incident “Unknown”</td>
<td>24</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>162</strong></td>
<td><strong>100.00%</strong></td>
</tr>
</tbody>
</table>

Why It Is Important to Report Allegations in a Timely Manner

- Late reporting exposes clients and staff members to increased/ongoing risk of harm.
- Late reporting can result in clients fearing for some days that no one will protect them.
- Late reports are often not as specific or accurate because memories of exactly what happened can fade.
- Late reporting usually results in some loss of physical evidence.
- Late reporting often signals a culture of staff/management retaliation for reporting complaints.
TABLE 3: DSHS-ASSIGNED INVESTIGATION INITIATION PRIORITY RATINGs FOR COMPLAINTS/ALLEGATIONS RELATED TO WAIVER-FUNDED SUPPORTED LIVING HOMES RECEIVED (JUNE – AUGUST 2011)\textsuperscript{5,6}

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-Day Investigation Initiation Priority</td>
<td>14</td>
</tr>
<tr>
<td>10-Day Investigation Initiation Priority</td>
<td>147</td>
</tr>
<tr>
<td>20-Day Investigation Initiation Priority</td>
<td>102</td>
</tr>
<tr>
<td>45-Day Investigation Initiation Priority</td>
<td>4</td>
</tr>
<tr>
<td>Unknown (no complaint form found in file)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>268</strong></td>
</tr>
</tbody>
</table>

**DSHS GUIDELINES FOR INVESTIGATION INITIATION PRIORITIES (RCS COMPLAINT PRIORITIES, DECEMBER 30, 2003)**

**2 working days:** This is an allegation of a life-threatening situation that has caused, or is at risk of causing, substantial harm of such consequence that urgent intervention is necessary. Complaint and incident investigations shall be initiated within 2 working days of receipt in the RCS field unit.

**10 working days:** This is an allegation of a situation that has caused harm, injury, or impairment to the resident. A timely response is indicated because the situation is present and ongoing, or there is high potential for reoccurrence of the incident. Complaint and incident investigations shall be initiated within 10 working days of receipt in the RCS field unit.

**20 working days:** This is an allegation of a situation for a resident that is not likely to reoccur, but if it did, would pose a risk of potential harm for that resident or other residents. The facility may have investigated the situation, and initiated corrective action. RCS investigation is required because of the need to determine whether the facility/home’s systems are intact. Complaint and incident investigations shall be initiated within 20 working days of receipt in the RCS field unit.

**45 working days:** This is an allegation of a situation that commonly involves the failure to provide general care and services. The resident has experienced no more than discomfort, and no significant impairment to physical, mental, or safety status. Complaint and incident investigations shall be initiated within 45 working days of receipt in the RCS field.

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\textsuperscript{5} These reports include the 162 unique cases sent to me related to two-day and ten-day investigation initiation reports for June – August 2011, as well as priority status data on 106 additional reports submitted to Disability Rights Washington by DSHS. It should be noted that the DSHS report of the number of 20-day and 45-day status cases for the period June – August 2011 likely included some duplicate complaints referencing the same or similar case, as I had identified 24 duplicate 20-day status cases associated with the 162 cases in the primary data base sample of 2-day and 10-day priority cases for June – August 2011. For the purpose of this analysis, the identified 24 duplicate 20-day cases were deleted, but readers should be aware that it is possible that additional cases in the 20-day subgroup may be duplicate complaints.

\textsuperscript{6} If a case was associated with two or more duplicate/similar complaints that had different priority statuses assigned, the highest (i.e., most immediate) priority was used in the analysis.
### Table 4: Days Delay in Initiating 2-Day Investigation Initiation Priority Cases (June – August 2011) *(n = 14)*

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 days or less</td>
<td>11</td>
</tr>
<tr>
<td>3 - 4 days</td>
<td>2</td>
</tr>
<tr>
<td>Unable to determine due to errors in dates recorded or missing dates</td>
<td>1</td>
</tr>
</tbody>
</table>

### Table 5: Days Delay in Initiating 10-Day Investigation Initiation Priority Cases (June – August 2011) *(n = 148)*

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 days or less</td>
<td>30</td>
</tr>
<tr>
<td>11 - 14 days (two weeks)</td>
<td>29</td>
</tr>
<tr>
<td>15 - 21 days (three weeks)</td>
<td>17</td>
</tr>
<tr>
<td>22 - 28 days (four weeks)</td>
<td>12</td>
</tr>
<tr>
<td>29 - 42 days (six weeks)</td>
<td>4</td>
</tr>
<tr>
<td>43 - 56 days (eight weeks)</td>
<td>2</td>
</tr>
<tr>
<td>57 – 70 days (ten weeks)</td>
<td>5</td>
</tr>
<tr>
<td>71 – 99 days (14 weeks)</td>
<td>6</td>
</tr>
<tr>
<td>100 - 199 days (ten weeks)</td>
<td>6</td>
</tr>
<tr>
<td>No Investigation was Completed</td>
<td>33</td>
</tr>
<tr>
<td>Unable to Determine Due to Errors in Dates or Missing Dates</td>
<td>4</td>
</tr>
<tr>
<td>148</td>
<td>99.00%</td>
</tr>
</tbody>
</table>

---

7 In the cases associated with two or more complaints, the calculation of the lapse between the date the case was referred and the date the case was initiated was done such that the briefest time period across the duplicate complaints was used. Note: also, one case (#125, Case Control # 11-07-21407) had no original complaint form in the record and thus its investigation initiation priority status was unknown.

8 In completing this analysis, cases #7a and 58a were deleted as their related cases #7b and 58b were classified as 2-day priority cases.
Why It Is Poor Practice to Delay the Initiation of Investigations

- Victims who are disabled may forget what happened or be unable to recount what happened consistently.
- Physical evidence may be lost.
- The scene of the incident may no longer be intact.
- Any injuries to the victim may have healed and no longer be visible.
- Witnesses may also forget or “go missing.”
- Alleged perpetrators may not be around any longer.
- Alleged perpetrators have time to re-construct their “stories” of what occurred.
- Victims feel abandoned by long delays in investigating.
- Delays in investigating discourage reporters from filing reports.
### Table 6: Days Lapsed Between Investigation Referral Date and Completion of the Investigation Summary Report\(^9\) (June – August 2011)

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>30 Days or Less</td>
<td>72</td>
</tr>
<tr>
<td>31 – 60 Days</td>
<td>17</td>
</tr>
<tr>
<td>61 – 90 Days</td>
<td>13</td>
</tr>
<tr>
<td>91 – 199 Days</td>
<td>27</td>
</tr>
<tr>
<td>No Investigation Was Completed</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>162</td>
</tr>
</tbody>
</table>

### Table 7: Days Lapsed Between “Completed” Investigation Date and Signature Date of RCS Field Manager (June – August 2011)

<table>
<thead>
<tr>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 7 Days</td>
<td>26</td>
</tr>
<tr>
<td>8 – 14 Days</td>
<td>14</td>
</tr>
<tr>
<td>15 – 30 Days</td>
<td>15</td>
</tr>
<tr>
<td>31 – 60 Days</td>
<td>11</td>
</tr>
<tr>
<td>61 – 90 Days</td>
<td>5</td>
</tr>
<tr>
<td>91 – 120 Days</td>
<td>13</td>
</tr>
<tr>
<td>121 – 150 Days</td>
<td>19</td>
</tr>
<tr>
<td>151 – 180 Days</td>
<td>14</td>
</tr>
<tr>
<td>181 – 211 Days</td>
<td>9</td>
</tr>
<tr>
<td>No Supervisory Review Documented</td>
<td>3</td>
</tr>
<tr>
<td>No Investigation Was Completed</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>162</td>
</tr>
</tbody>
</table>

\(^9\) As with other calculations, in the cases associated with duplicate complaints filed, if the time lapses between the date of referral of the case and the investigation completion differed for the associated complaints, the shortest time interval was used in this analysis.
Table 8: Resident and Client Protection Program’s (RCPP) Activities Related to the 162 Cases (June – August 2011)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number of Cases</th>
<th>Percent of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cases Investigated by RCPP</td>
<td>9</td>
<td>6%</td>
</tr>
<tr>
<td>Cases &quot;Reviewed&quot; by RCPP</td>
<td>15</td>
<td>9%</td>
</tr>
<tr>
<td>Cases Not Addressed by RCPP</td>
<td>138</td>
<td>85%</td>
</tr>
<tr>
<td></td>
<td>162</td>
<td>100.00%</td>
</tr>
</tbody>
</table>
ATTACHMENT B
CASE SUMMARIES ILLUSTRATING MAJOR FINDINGS

[Charts A-H on pages 22-29 omitted for Client Confidentiality]

Chart A: Case Examples Where the Complaint/Concerns Had Been “On-going”

Chart B: Examples of Cases Associated with Multiple Filed Complaints that were Assigned Different Investigation Initiation Priority Time Frames

Chart C: Cases Where the Start of the Investigation was Significantly Delayed

Chart D: Investigations Not Completed Until 91-199 Days After the Complaint was Filed

Chart E: Complaints for Which No State Investigation was Found

Chart F: Examples of Cases Where No Investigator Notes Were Found

Chart G: Examples of Cases Where Significant Complaints Were Not Addressed
<table>
<thead>
<tr>
<th>Case Number</th>
<th>Boxed Insert</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Different Investigation Priorities</td>
</tr>
<tr>
<td>18</td>
<td>Important issues not addressed in the investigation</td>
</tr>
<tr>
<td>20</td>
<td>Delayed Investigation Initiation</td>
</tr>
<tr>
<td>29</td>
<td>NO Investigation</td>
</tr>
<tr>
<td>30</td>
<td>NO Investigation</td>
</tr>
<tr>
<td>40</td>
<td>Delayed Investigation Completion</td>
</tr>
<tr>
<td>41</td>
<td>No investigator notes in the file</td>
</tr>
<tr>
<td>44</td>
<td>Abuse, no citation of failed provider practice &amp; no RCPP investigation</td>
</tr>
<tr>
<td>53</td>
<td>Ongoing</td>
</tr>
<tr>
<td>54</td>
<td>Ongoing</td>
</tr>
<tr>
<td>55</td>
<td>Delayed Investigation Completion</td>
</tr>
<tr>
<td>57</td>
<td>No investigator notes in the file</td>
</tr>
<tr>
<td>58</td>
<td>Different Investigation Priorities</td>
</tr>
<tr>
<td>58</td>
<td>Important issues not addressed in the investigation</td>
</tr>
<tr>
<td>59</td>
<td>Ongoing</td>
</tr>
<tr>
<td>63</td>
<td>NO Investigation</td>
</tr>
<tr>
<td>65</td>
<td>NO Investigation</td>
</tr>
<tr>
<td>72</td>
<td>Different Investigation Priorities</td>
</tr>
<tr>
<td>75</td>
<td>Abuse, no citation of failed provider practice &amp; no RCPP investigation</td>
</tr>
<tr>
<td>76</td>
<td>No investigator notes in the file</td>
</tr>
<tr>
<td>77</td>
<td>Delayed Investigation Initiation</td>
</tr>
<tr>
<td>78</td>
<td>Delayed Investigation Completion</td>
</tr>
<tr>
<td>83</td>
<td>Delayed Investigation Initiation</td>
</tr>
<tr>
<td>87</td>
<td>Delayed Investigation Completion</td>
</tr>
<tr>
<td>88</td>
<td>Abuse, no citation of failed provider practice &amp; no RCPP investigation</td>
</tr>
<tr>
<td>91</td>
<td>No investigator notes in the file</td>
</tr>
<tr>
<td>95</td>
<td>Delayed Investigation Initiation</td>
</tr>
<tr>
<td>96</td>
<td>Important issues not addressed in the investigation</td>
</tr>
<tr>
<td>97</td>
<td>Ongoing</td>
</tr>
<tr>
<td>99</td>
<td>NO Investigation</td>
</tr>
<tr>
<td>100</td>
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<td>105</td>
<td>Abuse, no citation of failed provider practice &amp; no RCPP investigation</td>
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<td>Abuse, no citation of failed provider practice &amp; no RCPP investigation</td>
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<td>109</td>
<td>No investigator notes in the file</td>
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<td>Important issues not addressed in the investigation</td>
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<td>Delayed Investigation Initiation</td>
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<td>Delayed Investigation Completion</td>
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<td>No investigator notes in the file</td>
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<td>158</td>
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</tr>
<tr>
<td>170</td>
<td>Delayed Investigation Initiation</td>
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</tbody>
</table>

**CASE NUMBERS FOR EXAMPLES BY TYPES OF INCIDENTS**

**CLIENT-TO-CLIENT ABUSE/ASSAULTS**
13
20
38
56
74
103
113
125

**INJURY OF UNKNOWN ORIGIN**
17
31
159

**SEXUAL ABUSE**
66
72
114
156

**SUBSTANCE ABUSE (BY CLIENT)**
64
July 31, 2012

Susan Kas
Disability Rights Washington
315 Fifth Avenue, Suite 850
Seattle, Washington 98104

Dear Ms. Kas;

As requested, I have reviewed the second set of investigation documents sent to me in late July 2012. In this letter, which constitutes a supplement report to my initial report, I have shared my specific findings related to these investigations. As reflected in these findings, my review of these documents has not fundamentally altered the conclusions in my initial report.

Specifically, although the documents do yield completed investigations for 24 of the 33 cases for which my initial report stated that no investigation was completed, these investigations (with one questionable exception) were not completed until more than six months after complaints were filed, and in almost all cases, the significant delays in the initiation and completion of these investigations critically compromised the findings of facts in the investigations.

The review of the additional documents also further confirmed that the Department of Social and Health Services’ (DSHS’) procedures and practices do not assure accountability of complaints received or the appropriate supervision of investigators. The documents indicated that all of complaints referenced had been assigned to investigators proximate with the date they were filed, but investigators had apparently lost track of these assignments, and in virtually all cases, there was no documented evidence that the investigations had been initiated or that supervisors had intervened.

The documents also shed additional light on the unreliability of DSHS’ assignment of investigation initiation priorities for filed complaints. For approximately one-fourth of the 35 complaints referenced in the documents, the investigation initiation priorities had “changed” from their initially designated 10-day initiation priority to a “quality review” priority, which essentially meant that no investigation would be done. It was also not apparent when or why these changes were made and no documentation justifying these changes was found. Nor was there evidence that the complainants had been informed of these administrative decisions not to investigate their complaints.
Finally, as reflected below, I also found similar problems in many of these late-completed investigations themselves. Many of the problems could be traced back to the tardiness of the investigations, but others (as also noted in my initial report) reflected the investigators’ failure to address significant issues, including allegations of abuse and neglect. In addition, as noted in my initial report, these investigations continued to manifest a trend of very “conservative” determinations of no citations for “failed provider practice,” even in instances when investigation documents explicitly referenced failed practices.

*******************************

SPECIFIC FINDINGS

- This report discusses a set of investigation documents associated with 26 complaints which were filed in the period June – August 2011. I received these documents in late July 2012 after I had submitted my initial report to you on the investigations of complaints/allegations filed with DSHS during June – August 2011.

- These documents were reportedly submitted to Disability Rights Washington by DSHS subsequent to DSHS’ initial document production. These documents related to 35 complaints filed during the period June – August 2011, which had been assigned a 2-day or a 10-day investigation initiation priority status, but for which no investigation report was initially produced.

- The documents included 26 investigation files which were associated with 26 of the 35 above-referenced complaints. No investigations were submitted for nine of the identified 35 cases. A listing of the 35 cases enclosed with the documents indicated that these nine cases for which no investigation had been submitted had at some later point in time been re-classified from a 10-day investigation initiation status to a “quality review” status, which essentially means that DSHS had later determined no investigation was warranted for these complaints. No documentation was submitted justifying these changes, the dates the changes were made, or if the subsequent State determination not to investigate the complaints had been communicated to the original complainants.

- It should also be noted that I discovered in my review of the documents two complaint investigation reports (# 11-08- and # 11-08-) for which I had already received investigation reports. Information on these two cases was included in my initial report and therefore is not reflected in this supplemental report.

- In all, the documents received addressed 24 of the 33 cases referenced in my initial report as having no investigation completed. They did not include investigations for the nine cases which had been re-classified to have a “quality review” investigation
initiation status and one additional complaint (#11-08- ) for which I located no investigation in the original set of documents sent to me.

- Notably, documents associated with all 24 of the new late investigations referenced that DSHS had assigned the complaint for investigation one to three days from the date the complaint was received. None of the documents, however, referenced why the investigations had not been initiated/completed.

- According to the summary investigation reports in the file, investigations of seven of these cases were also “reportedly” initiated soon after they were assigned. Of note, however, in almost all of these cases, investigator’s notes usually did not explicitly reference investigative activities or observations proximate with this reported start date. Rather, most often documented investigative activities were dated months after the documented investigation initiation dates on the Residential Care Services Division (RCS) investigative report summary. For this reason, I found the documented investigation initiation dates of these seven cases suspect.

- For the remaining 17 investigations, the documented investigation initiation dates were all in 2012. The investigation of one of these cases (#11-08- ) was initiated in January 2012; three other case investigations (#11-07- ; #11-08- ; #11-08- ) were initiated in February 2012; and 13 case investigations were initiated in March 2012.

- Of the above 17 investigations, all were initiated more than 173 days after the complaint was filed and 14 were initiated more than 209 days after the complaint was initiated. As noted in my initial report, these delays in the initiation of investigations fundamentally compromised the investigator’s ability to achieve reliable and valid investigative findings.

- Reflective of the significant delays in the initiation of the investigations of the late-submitted cases, investigations were also completed many months after the complaint was reported.

  - Only one of the investigations (#11-06- ) was completed in 2011 and dates of this investigation are suspect. The investigation summary report noted that the investigation was completed on 6/8/2011, but the complaint was received a day later on 6/9/2011. There was no explanation in the file for these apparently implausible dates.

  - Of the remaining cases, almost all were completed in March 2012, but one was completed in February 2012 and three were completed in April 2012.
The time lapse between the dates complaints were filed and investigations completed for these cases (excepting the one unusual case with implausible dates referenced above) ranged from 189 days to 258 days, with the majority of the investigations not being completed until seven or more months after the complaints were filed. Such significant delays in the completion of investigations left the alleged vulnerable disabled victims at risk of harm for extended periods of time. As noted below, in some cases, victims suffered repeated harm due to these delays.

- In addition to their tardiness and likely in large part due to their tardiness, most of these investigations also had significant flaws. Below, I have provided a number of examples of the problems identified.

**DRW Note: Ten case examples discussed on pages 4-7 are omitted for client confidentiality**
Please let me know if you have any questions about this supplemental report.

Sincerely,

Nancy K. Ray, Ed.D.
President
NKR & Associates, Inc.
Appendix C
August 6, 2012

Susan Kas
Disability Rights Washington
315 5th Avenue South, Suite 850
Seattle, WA  98104

Re:  DUANE BOYLE, through his guardians Marion and Robert Boyle, et al.,
v.
SUSAN N. DREYFUS, in her official capacity as the secretary of the Washington
Department of Social and Health Services
NO. C01-5687 JKA

Dear Susan,

Please find enclosed the Report by Sue A. Gant, Ph.D. in the above referenced matter along with the related attachments

Sincerely,

Sue A Gant

Sue A. Gant  Ph.D.

SAG: rhy
enclosures.
DUANE BOYLE, through his guardians Marion and Robert Boyle, et al.,

v.

SUSAN N. DREYFUS, in her official capacity as the secretary of the Washington Department of Social and Health Services

NO. C01-5687 JKA

UNITED STATES DISTRICT COURT
WESTERN DISTRICT OF WASHINGTON
AT TACOMA

August 6, 2012
Submitted By:
Sue A. Gant, Ph.D.,
Gant, Yackel and Associates Inc.
PURPOSE

I have been retained by Disability Rights Washington (DRW), plaintiffs’ counsel, in the matter of Boyle v. Arnold to complete a review of documents and offer professional opinions about Defendant’s compliance with her obligation to implement a quality management strategy (QMS) as required by Settlement Agreement Section II.B.9: specifically implementation of the Washington Home and Community Based Waiver (HCBW) Quality Management, Mortality Review Process.

CLAIMS AT ISSUE

The parties in Boyle v. Arnold-Williams, Cause No. C-01-5687-JKA entered into a Settlement Agreement (“Agreement”) filed 5/20/10 with the goal of ultimately resolving claims brought on behalf of the four individual Plaintiffs, Disability Rights Washington, and the Settlement Class regarding the HCBS waiver programs for people with developmental disabilities.

On May 25, 2012 Plaintiffs respectfully requested an Order of Contempt be entered against the Defendant in the above captioned case for her failure to substantially comply with the Amended Order and Settlement Agreement (Dkt. 237). The Motion for Contempt was noted for Hearing with Oral Argument: August 31, 2012.

STATEMENT OF EXPERT OPINION

I, Sue A. Gant, do hereby declare: based on my four decades of experience in the field of quality assurance of services for individuals with developmental disabilities and my review of the Defendant’s quality management strategy-mortality review related policies, procedures and practices, the Defendant has substantially failed to comply with the Amended Order and Settlement Agreement (Dkt. 237), Section II.B.9

1). Defendant’s Mortality Review process is so flawed it does not serve as a safeguard to protect plaintiffs’ health and safety;

2). There are multiple discrepancies among various sources about the reporting, investigation, review and use of information of the death of a waiver participant it renders the process ineffective in protecting plaintiffs’ health and safety. Sources where information conflicts include:

- Application for a §1915 (c) HCBS Waiver: Version 3.3, Submitted by State of Washington Department of Social and Health Services (DSHS) Aging and Disability Services Administration (ADSA) Division of Developmental Disabilities (DDD) State of Washington, November 1, 2006; Appendix H;
- DHSH policies related to death of CORE and Community Protection waiver participants in effect as of June 1, 2011-December 31, 2011;
- The electronic DDD Mortality Review Log;

1 “Plaintiffs” for purposes of this Settlement Agreement only, means the four individual Plaintiffs, Duane Boyle, Douglas J. Fenner, Dennis O’Neill and Alisha Presson, Disability Rights Washington and the “Settlement Class” that includes all current and future participants in Washington State’s Medicaid Home and Community Based Services (HCBS) Waiver programs for people with developmental disabilities.

2 “Defendant” for purposes of this Settlement Agreement only, means the Secretary of the Washington State Department of Social and Health Services (DSHS), in her official capacity and any successor(s).
3. There is a lack of evidence that the following quality management activities (a-d; g-j) agreed to by defendants (Settlement Agreement) are elements studied and employed during a mortality review and information is used to determine if any relationship to cause of death:

   (a) Timeliness of assessments;
   (b) Quality and comprehensiveness of assessments;
   (c) Timeliness, quality and comprehensiveness of plans of care and service plans including reasonable promptness;
   (d) Delivery of services contained in service plans including reasonable promptness;
   (g) Monitoring providers for adherence to waiver requirements;
   (h) Staff Training;
   (i) Monitoring of waiver participants' health and welfare;
   (j) Efforts to identify, address and minimize instances of abuse, neglect or exploitation.

4. Mortality reporting, investigation and review policies are generally not followed nor enforced.

5. Reports of death lack a standard set of facts about the death that provides essential information about the deceased and the circumstances of death (what, where, when and how). There is considerable variance in the amount and type of information reported, affecting the quality of the initial review and reviewers’ response.

6. Reports of death from the provider (DDD Mortality Review Part 1), lack review and remediation for missing required information including identifiers of the deceased, time of death, and circumstances of death.

7. Failure to require and enforce timely and complete reporting of serious incidents including death of an individual with DD while receiving public funded services is contrary to best practice and impedes the conduct of a professionally adequate investigation and critical review of the circumstances of death.

8. DHSH fails to organize mortality review in a manner where providers are mandated to submit a standard set of documents about the deceased and care provided; provider compliance with providing the documents is monitored and actions taken when providers do not comply. Incomplete information about the deceased and events that potentially affected the death renders the accuracy of an investigation and review unreliable, thus useless.

9. Incidents of abuse or neglect related deaths are not consistently referred by DDD for investigation.

10. There is an absence of interagency (DDD, APS, CPS and RCS) coordination in the identification and response to deaths and to identify, track, trend, and remediate instances of abuse and/or neglect.

11. There is an absence of interagency (DDD, APS, CPS and RCS) coordination in the identification and response to preventable deaths and to identify, track, trend, and reduce/eliminate preventable deaths.

12. Mortality Review Committee membership does not include stakeholder or advocacy representation.
13). There is no record of Mortality Review Team (MRT) meeting activities including agenda, participants including signatures of any DSHS employee indicating they participated in each Mortality Review conducted; review findings, and recommendations for improvement and follow-up to determine implementation of remedial actions to close the quality improvement loop.

14). Mortality review policy does not address requisites of an effective team meeting: designated chairperson, defined quorum, agenda and criteria used to develop the agenda, length/time of meeting, strategy for reaching consensus, expected agenda outcome, strategy for identifying members responsible for follow-up actions, and method used to close agenda items.

15.) There is no documented evidence of recommendations resulting from any Mortality Review conducted

16). Mortality reviewers do not detect problems with the decedent’s continuity of care and do not address the problems with remedial action.

17). The DDD electronic system used to track mortality reporting and review process and practice lacks reliability.

18). The DDD Mortality Review Tracking Chart (Bates 20000016 – 20000073) specify “Materials Used in Review” and “Further Materials Needed,” There is no evidence the DDD Mortality Review Team received and/or used the materials to conduct and/or complete reviews.

19). There is an absence of evidence that reviewers conduct a critical study of the facts and offer an opinion about quality of care or clinical services delivered in a caring and a competent environment.

20). There is no evidence the findings are disseminated throughout DSHS for systemic quality improvement.

21). There is no evidence information about deaths including cause for preventable deaths are aggregated and used to drive policy and quality improvement activities.

22). There is no evidence information about deaths and mortality review findings are integrated with other quality assurance information to improve quality.

23.) There is no evidence of analysis of death by region, provider (residential, day services, case resource management) to determine patterns and remedial actions.

24.) There is no evidence of analysis findings for death by end of life status (DNR, POLST\(^3\)), policy compliance and remedial actions.

25). There is no evidence of analysis findings for supports and services at time of death (hospice, palliative care, intensive community based medical services, acute care hospitalization, intensive care hospitalization) to

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\(^3\) The Physician Orders for Life-Sustaining Treatment (POLST) form, represents a way of summarizing wishes of an individual regarding life-sustaining treatment. The form is intended for any individual with an advanced life-limiting illness; it facilitates the process of translating end-of-life discussions with patients into actual treatment decisions, and provides security for the individual and physician that expressed wishes will be carried out. There is no other form that streamlines the process in this way. In a health care facility, it should be the first document in the clinical record. It is recognized as a set of physician orders, to be implemented as any physicians orders would. At home the bright green form should be located in a prominent location. It will be recognized by emergency personnel as orders to be followed.
determine frequency of use and quality of clinical services and end of life support and remedial actions to improve quality.

26). There is no evidence of review and analysis for promptness of actions associated with detection of signs and symptoms of deteriorating health and response including delivery of nursing services, use of emergency services-911, Urgent Care, Emergency Room- and quality of services delivered by DDD provider (as defined by WAC), emergency responders, and urgent/emergency care licensed practitioners and actions taken to address any deviation from accepted standards of practice.

27.) There is no evidence the MRT analyzes findings of medication use by type (psychotropic/anti-convulsants, analgesics, narcotics, hypnotics, sedatives, anti-diabetic, bisphosphonates and anti-hypertensives) of deceased waiver participants by individual, provider, and statewide; studies patterns or trends, recommends remedial actions, verifies implementation of recommendations, and determines effectiveness of intervention by measuring impact.

28). There is no evidence Mortality data is used to reduce morbidity by the study of health issues identified during mortality review including by example: recurrent UTIs, chronic constipation, rapid weight loss, unresolved melanoma without remission; cancers, and diabetes-morbid and moderate obesity; and recommended educational opportunities i.e. Use of critical pathways to recognize signs and symptoms of deteriorating health and proper response.

29). Mortality reviews and investigations of abuse and neglect to use risk management information including history of incidents threatening life safety, investigation results, provider compliance review findings, and corrective actions to inform, drive actions, and measure outcome of actions to prevent premature death.

30). The DDD Mortality Review Team (MRT) fails to comply with DDD Policy 7.05 that requires the MRT DDD produce an annual report to DDD executive management including recommendations to the Office of Quality Programs and Services concerning needed training, policy changes, and other related issues. The 2009-2010 Mortality Report includes information about deaths is limited to: age at time of death, gender, type of residence, and cause compared to National CDC findings and State of Washington.

31). Incident management is not an effective safeguard to protect plaintiffs’ health and safety.

32). RCS does not use history of incidents threatening life safety, prior abuse and neglect investigation results, provider compliance review findings, and respective plans of correction to detect a pattern of deficient practices and relationship to circumstances of death.

33). RCS and DDD failure to monitor and enforce implementation of waiver provider plans of correction to remove threats to life safety when abuse/neglect substantiated and/or provider compliance reviews find deficiencies cause deaths that could have been prevented had the provider been held accountable for removal of the threat.

The list of documents, materials and testimony I used to support my findings and opinions can be found in the following Methodology section of this report. General and Specific Findings and Opinions are also included. My qualifications, publications, and cases in which I testified as an expert at trial or by deposition are listed in my resume that is attached to the report, as is my Statement of Compensation.
QUALIFICATIONS TO OFFER EXPERT OPINION

I am an independent consultant residing in Hawarden, Iowa. I am a Doctor of developmental psychology and human learning and behavior analysis specializing in program development and evaluation of services for persons with developmental disabilities.

I am qualified to offer an expert opinion as I have extensive expertise in the field of developmental disabilities and quality assurance.

I have extensive experience and professional expertise with regard to the provision of adequate and appropriate protections, supports, and services, in community settings, to persons with intellectual disability and/or other developmental disabilities, including persons with dual diagnosis of a developmental disability and co-occurring mental illness. I have worked with individuals from a broad range of age groups and with a wide variety of disabilities, including those persons with extensive health care and/or behavior challenges. Over the years I have provided direct service and technical assistance and/or quality review and monitoring for both individual and systemic matters, on behalf of interested actors on all sides, including persons with developmental disabilities, families, advocates, community providers, the federal government, several state/territorial governments (including Connecticut, Kentucky, Massachusetts, Texas and the United States Virgin Islands), as well as a number of United States federal, state, and local courts. Typically, my work relates to protections from harm, the provision of education and training, behavior supports, risk management, quality assurance, and planning for transition from an out of home segregated placement back to a socially integrated community.

I am the Vice-President of the consulting firm Gant, Yackel & Associates Inc. I have over 30 years’ experience working in the field of developmental disabilities. I have a Doctorate in Educational Psychology from Southern Illinois University, specializing in Developmental Disabilities Program Development and Evaluation. I worked at a public facility for persons with developmental disability in Illinois and in Connecticut served as executive assistant to the Commissioner for Developmental Disability Services by directing the Division of Quality Assurance. I have extensive familiarity with standards of care applicable to integrated community services for individuals with developmental disability. I have taught university-level courses in education, special education, and educational psychology. I have been appointed by United States District Courts to serve as Court Monitor, Special Master, and Expert to the Court in cases involving people with developmental disabilities institutionalized and returned to their communities. These cases include Lelsz v. Kavanagh, C.A. -3-85-2462 A. (N.D. Tx.), Halderman et al. v. Pennhurst State School and Hospital et al., C. A. No. 74-1345, United States v. Oregon, No. CV-86-961-LE (D. Or.), Gary W. v. Louisiana, C.A. No. 74-2412 (E.D. La.) and Jackson v. Ft Stanton, C.A. No. 87-0839, D. NM. I have acted as consultant and expert witness for the United States Department of Justice (DOJ), Civil Rights Division in actions under the Civil Rights of Institutionalized Persons Act (CRIPA) and the American Disabilities Act (ADA) and the United States Department of Justice (DOJ), Equal Employment Opportunity Commission (EEOC) and the American Disabilities Act (ADA).

I have conducted thousands of evaluations and crafted remedial plans for individual and system reform in Illinois, New York, Louisiana, Michigan, Connecticut, Iowa, New Mexico, Arkansas, Maryland, Oregon, Utah, Washington, Texas, Indiana, Virginia, California, and Georgia. As a Program Associate with the Willowbrook Review Panel, the Court appointed monitors in New York Association of Retarded Citizens v. Carey, I was responsible for monitoring quality of care and treatment of thousands of Willowbrook class members that resided in six (6) public facilities and were moving to community integrated settings. I developed policy and
procedures and evaluation tools in conjunction with New York government employees; evaluated policy implementation; constructed remedial plans to address deficient practices; monitored implementation of the remedial plans; and provided periodic status reports to the Court.

As part of my professional experience, I have reviewed case records for thousands of individuals with intellectual and/or developmental disabilities in congregate and segregated settings and integrated community residential environments. Purpose of review included examination of quality of care, adequacy of protections from harm and actions taken to remove any threats of harm. I have reviewed records of hundreds of deceased individuals with intellectual and/or developmental disabilities, corresponding mortality reviews, and plans of actions to prevent adverse health outcomes and improve quality of services for individuals with intellectual and/or developmental disabilities. I administered and chaired the Connecticut Department of Developmental Disabilities Services (formerly Mental Retardation) Mortality Review process: have evaluated Mortality Review Committee (MRC) activities through record review and direct observation, participated in MRC meetings as an ad hoc MRC member and made recommendations for system improvements in quality assurance policies and practices, including incident management of death reports and investigations and mortality review, during my work with the federal government and federal district courts. I have evaluated dozens of cases of deceased individuals with developmental disabilities receiving services in community settings at the time of their death for the purpose of determining if the quality of care and treatment contributed to the individual’s death.

I am extensively familiar with the supports and services, which are generally provided to individuals with intellectual and/or developmental disabilities.

United States federal and state courts have qualified me as an expert in quality assurance of services for individuals with intellectual and/or developmental disabilities.

**METHODOLOGY**

I have reviewed thousands of pages of documents from various sources, as provided by Disability Rights Washington. Sources included:

4. DDD Policy 7.05: Mortality Reviews Issued: 5/09; Effective 5/1/09-1/3/2012.
5. DDD Policy 7.05: Mortality Reviews Issued: Issued: 1/12; Approved January 3/2012; Supersession: DDD policy 7.05 Issued May 01, 2009.
6. DDD policy 12.01: Incident Reporting Issued: 2/12; Supersession DDD policy 12.01 Issued September 16, 2009.
8. DDD Policy 6.09: Operational Reporting Requirements for Residential Services Providers (D.) Clients with a Do Not Resuscitate (DNR) Order: Issued 7/09; Supersession: None.
10. Documents that Defendant’s counsel has represented as responsive to plaintiffs’ document requests:
   RCS investigation and DDD review of plaintiff class deaths June 1-December 31, 2011; DSHS/DDD
   Electronic Data Entry of Mortality Review in a PDF chart format (bates stamped 2000016-20000073).

11. DDD Mortality Report 2010 and 2011, Dated 7/2012 (34 pages/slides) transmitted to DRWA July 19,
    2012.


13. Source File for CMS Assurance for Basic, Basic Plus, Core, Community Protection Waivers Year
    2009-2010.


15. Sample RCS Completed Forms; Complaint Intake and Routing Form; RCS Investigations with related
    documents.

16. RCS and DDD records for class members KY (July 2011), JW (July 2011), and BO. (August 2011)


21. E-mail exchanges between defendants’ and plaintiffs’ counsel clarifying document productions.

I analyzed information gleaned from mortality related documents of a sample of Community Protection Program
and Core waiver participants that died between June 1 and December 31, 2011. Sample size varied based on
source information availability. Sample size and source of information is identified in the findings and opinions
section of the report. A list by name and date of death studied is attached to the report.

The names, date and cause of death for Community Protection Program and Core Waiver participant deaths,
June 1 and December 31, 2011, regardless of whether a Mortality Review was conducted was not received for
review.

The following observations and opinions are based on the information gleaned from these multiple sources.
Other information will be taken into account as it becomes available.

BACKGROUND

The parties in Boyle v. Arnold-Williams, Case No. C-01-5687-JKA entered into a Settlement Agreement
(“Agreement”) filed 5/20/10 with the goal of ultimately resolving claims brought on behalf of the four individual
Plaintiffs, Disability Rights Washington, and the Settlement Class regarding the HCBS waiver programs\(^5\) for
people with developmental disabilities.

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\(^5\) The waiver serves 4,237 individuals, with an average annual cost per participant of $74,979. The Washington Aging and Disability
Services Administration (ADSA), Division of Developmental Disabilities (DDD) is the Medicaid Agency responsible for
administering HCBS DD services in Washington.
The Defendant, the Secretary of Washington Department of Social and Health Services (DSHS), agreed to implement a quality management strategy (QMS), Settlement Agreement Section II.B.9. The areas addressed by this QMS are to include the following:

(a) Timeliness of assessments;
(b) Monitoring of the quality and comprehensiveness of assessments;
(c) Timeliness, quality and comprehensiveness of plans of care and service plans including reasonable promptness;
(d) Delivery of services contained in service plans including reasonable promptness;
(e) Freedom of Choice;
(f) Verification of provider qualifications;
(g) Monitoring providers for adherence to waiver requirements;
(h) Staff Training;
(i) Monitoring of waiver participants’ health and welfare;
(j) Efforts to identify address and minimize instances of abuse, neglect or exploitation.

The Defendant’s compliance with the Settlement Agreement - Quality Management Strategy is contingent on the Department of Social and Health Services (DSHS) ability to operationalize its commitments to protect the safety and improve the health of WA citizens with DDD. DSHS commitment to quality is promoted by the DSHS mission statement and articulated in its CMS Medicaid Home and Community-Based Services (HCBS) waiver application.  

The waiver application is based on the HCBS Quality Framework. The Framework focuses on seven broad, participant-centered desired outcomes for the delivery of waiver services, including assuring participant health and welfare.

DSHS gave CMS assurances that necessary safeguards have been taken to protect the health and welfare of persons receiving services under the waiver. The DSHS reported to CMS that DSHS has, “a formal, comprehensive system to ensure that the waiver meets the assurances and other requirements contained in this application. Through an ongoing process of discovery, remediation and improvement, the State assures the health and welfare of participants by monitoring: (a) level of care determinations; (b) individual plans and services delivery; (c) provider qualifications; (d) participant health and welfare; (e) financial oversight and (f) administrative oversight of the waiver. The State further assures that all problems identified through its discovery processes are addressed in an appropriate and timely manner, consistent with the severity and nature of the problem.” DSHS also made the commitment, “During the period that the waiver is in effect, the State will implement the Quality Management Strategy specified in Appendix H.”

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6 The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized in §1915(c) of the Social Security Act. The program permits a State to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization.

Strategy (QMS) implementation promised CMS is the same as DSHS agreed to implement in the Boyle v. Arnold-Williams Settlement Agreement.

Relevant Washington Social and Health Services Government Organizational Structure

The Washington Aging and Disability Services Administration (ADSA) is one of the administrations within DSHS.

- Division of Developmental Disabilities (DDD), a division within ADSA, is the Medicaid Agency responsible for administering HCBS DD services in Washington.
- DDD provides services to individuals (birth to death) with diagnoses of developmental disabilities based on assessed need.8
- Home and Community Services (HCS) Division, also a division within ADSA, administers the Adult Protective Services (APS)

Adult Protective Services is a program within the HCS Division and is mandated by law to provide protective services to vulnerable adults9 living in the community: they receive reports and investigate allegations of abuse, abandonment, neglect, self-neglect and financial exploitation.

- A separate division within ADSA, Residential Care Services (RCS) is the regulatory authority for residential long-term care settings and handles all intakes and investigations of alleged abuse against vulnerable adults when the alleged victim and the perpetrator are within a licensed/certified facility. Each division refers reports to the other Divisions within DSHS as appropriate.
- Complaint Resolution Unit (CRU), a unit within Residential Care Services (RCS) Division investigates complaints in residential facilities. CRU is the intake unit that assigns the complaints for investigation and the initiation deadline. The deadlines are stated as 2, 10, 20, 45 working day priority from most serious to least. Vast majority of cases get assigned 10 working days.

Under state authority, Child Protective Services (CPS) within the Children’s Administration (CA) of the Department of Social and Health Services (DSHS) is responsible for receiving and investigating reports of suspected child abuse and neglect.

DSHS “Source File for CMS Assurances: Division of Developmental Disabilities’ Data to Support CMS Assurances for Waivers, Waiver Years 2009 to 2010” to CMS

In December 2010 CMS conducted a review of Washington’s DSDS waiver. The review focused on statutory requirements under Section 1915(c)(2)(A) of the Act requiring states to assure that necessary safeguards have been taken to protect participants’ health and welfare; Specifically, the review focused on the extent which the policies and procedures have been implemented and the results of the State’s oversight activities. The State

8 The CARE system includes the DDD Assessment which incorporates proven assessment tools that have passed critical validity tests to support their use in measuring the support needs of people with chronic illnesses/conditions and people of all ages with developmental disabilities. These assessment tools include the Minimum Data Set (MDS), the Mini-Mental Status Exam (MMSE), the Centers for Epidemiological Studies (CESD)-Iowa Depression Scale, the Cognitive Performance Scale, the Zarit-Burden Scale (an alcohol/substance abuse screening tool) and the Supports Intensity Scale (SIS).
provided evidence of how it identified quality related issues and corrective actions taken. CMS reviewed its findings with the State staff during an exit interview conducted December 2010 following the review.

The CMS Final Report was not provided to the state until April 10, 2012 evaluating Washington's Home and Community-Based Services (HCBS) Core Waiver (#0410). The CMS review documented that the State was in partial compliance with federal waiver requirements in December 2010.

I found problems in 2012 with the reporting, investigation, and review of waiver participant' deaths that illustrate DSHS has not taken necessary safeguards to protect participants’ health and welfare contrary to the assurances given CMS in 2010.

The assurances DSHS “Source File for CMS Assurances: Division of Developmental Disabilities’ Data to Support CMS Assurances for Waivers, Waiver Years 2009 to 2010” related to deaths of waiver participants is limited to the following:

- Assurance – The state on an ongoing basis identifies, addresses and seeks to prevent the occurrence of abuse, neglect and exploitation
- Performance Measure #7: The Percentage of waiver participants whose death was subject to review that were reviewed by the DDD Mortality Review Team (MRT). DSHS reported to CMS 100% of waiver participants whose death was subject to review were reviewed by the DDD Mortality Review Team.
- Performance Measure # 8: The number of waiver recipient deaths reviewed by the Mortality Review Team (MRT) by cause of death. DDD has identified the number one cause of death as pneumonia (aspiration type). In response, DDD has developed training for providers, case managers, and caregiver alerts. DDD is working collaboratively with the University of Washington and the State of New Mexico to identify preventative strategies.
- DDD conducts a systematic review of the deaths of individuals served by residential programs funded or authorized by the Division of Developmental Disabilities (DDD).
- For community deaths the mortality review process includes a report from the provider, a report from the Regional Quality Assurance staff, signatures from the case manager and regional administrator and a final review by a multidisciplinary committee at Central Office; and
- System issues or other areas of concern are shared with the Full Management Team (FMT) at quarterly management meetings.

INTRODUCTION

The Federal government uses mortality rates as performance targets. Healthy People 2000, 2010 and 2020, a collaboration of U.S. government agencies, public health organizations and health sciences have common

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10 Healthy People started in January 2000 by the US Department of Health and Human Services, is a ten-year nationwide health promotion and disease prevention program developed through a broad consultation process, built on the best scientific knowledge and designed to measure programs over time. It is composed of objectives with focus areas and two overarching goals: 1) increase quality and years of healthy life and 2) eliminate health disparities. The goal of Healthy People 2000, was to
goals related to morbidity and mortality disparities between people with disabilities and the general population. The Centers for Medicare and Medicaid Services (CMS) use mortality rates as performance targets when measuring health outcomes.

The CMS Home and Community Based Waiver (HCBW) requires Performance Measures across 6 assurances. Health and Welfare is a key assurance of quality and mortality review is included as a performance measure.

A 2008 US Government Accountability Office (GAO) reports to CMS about the HCBW program, identified a need for CMS to ensure States had systematic methods to provide adequate safeguards and minimize unexpected deaths. GAO discussed Mortality review for individuals with developmental disabilities to reduce risk by using information to guide system improvement.

The federal government’s expectation that States have adequate safeguards to minimize unexpected deaths through Mortality review is consistent with practice for comprehensive quality assurance (QA) systems. (GAO-08-529)

Critical components of a Mortality Review system include:

- A dynamic uniform reporting process that ensures all deaths are immediately reported to the state level department and standard death report forms submitted within 24 hours of the death notification
- Screen individual death reports with standard information
- Standardized mortality review process (local, regional and state)
- Medical professionals participate in the process
- External stakeholders are included in the review process
- State level interdisciplinary/independent of mortality review committee/board aggregates mortality data over time to identify trends
- Direct link between mortality findings and improvement
- Document mortality information
- Produce periodic reports
- Publicly Report findings and improvements

Comprehensive QA systems value Mortality Review as it provides an abundance of information about the health and welfare of service recipients. Mortality review processes provide a retrospective analysis that assures compliance with standards, reduces adverse events, leads to ongoing improvement, and generates changes; Changes in policy and procedure or protocols, development practice standards, focused training systems, and improvement strategies.

An important component of any QA system is risk management activities that involve the analysis and review of deaths to identify important patterns and trends that may help increase knowledge about risk factors and reduce health disparities among Americans. In Healthy People 2010, to eliminate, not just reduce, disparities. In Healthy People 2020, that goal was expanded even further: to achieve health equity, eliminate disparities, and improve the health of all groups.,

provide information to guide systems enhancements. This requires a planned organization wide approach to design performance measurement, analysis and improvement by collecting information pertaining to the deaths of all individuals served by the organization. A mortality review system is a valuable quality assurance mechanism providing information to trigger corrective action and reduce future risk. The review process outcome should provide sufficient information and critical analysis so the following questions can be answered:

- Was the death anticipated or unexpected?
- Could this death have been prevented?
- Are there systems issues identified in the course of the review?
- Are there case specific issues identified in the course of the review?
- What actions should the state agency take to improve the health and safety of its consumers?

To accomplish these goals the state level mortality review must first take steps to identify system issues by compiling and synthesizing findings (problems) from the investigations and local/ regional and external reviews. Next, all recommendations for improvement (problem resolution) that arise from local/ regional and external reviews must be compiled and discussed at the state review level. The final steps in the problem resolution process is assigning responsibility to implement the quality improvement recommendations (strategies) and verifying recommendation(s) implementation- closing the information loop. This process must occur at an individual, provider, region and state level.

The effect of quality improvement strategies is then studied (by examining pre-determined indicators/ measures) to determine if the goal-to protect health and welfare- has been met.

The following report provides findings, opinions and conclusions about the Washington DSHS Mortality Review system. Case examples of deceased class members and my analysis of the reporting and review of each case can be found as an attachment to this report.

FINDINGS AND OPINIONS

Names of the Boyle class members deceased June 2011-December 31, 2011 that were reviewed by the DDD MRT per the electronic DDD Mortality Review Log and deceased waiver participants listed in chart “Death and complete and all DDD region and Central Office incidents and DDD Aware: 6/1/2011-12/31/2011” (Attachment A). The deceased and their cause of death can be found in Attachment B.

Policy and Practice Analysis

The Division of Developmental Disabilities (DDD) represents on its HCBS Waiver applications that it “has formalized waiver quality assurance processes to meet and maintain high quality standards.” (Home & Community Based Services (HCBS) Waiver Application Appendix H.) The DDD claims that these processes assure quality in the system by requiring “continuous monitoring” of health and welfare of waiver participants and remediation “when appropriate.” (Id.) The Mortality Review is purported to be one of the measures to assure quality. In Appendix H, the DDD represents that its Mortality Review Team reviews trends and patterns and makes recommendations on a monthly basis. (Id.) According to Appendix H, the Mortality review team utilizes, not only the IR system data and Mortality Reviews, but also the sophisticated statistical techniques and quality controls, Sigma six charts and Pareto Analysis. (Id.)
The actual Policies promulgated by the DDD for dealing with Mortality Reviews are filled with inconsistent processes, incomprehensible standards, and insubstantial review and remediation. The “formalized process” for review of deaths of DDD clients is found in DDD Policy 7.05 Mortality Reviews and DDD Policy 12.01 Incident Reporting. The initial reporting responsibilities under these policies are set forth in Reporting, Investigation, and Reviewing Deaths: Chart Displaying Inconsistencies and Incomplete Processes in Washing DDD Policy 12.01 and 7.05.

Initial Reporting of Death

It is unclear why the DDD policy dictates such varied processes for different types of programs/settings. For RHCs and ICF/IDs under Section A, no specific form is indicated and no reporting time frame is set forth. Although Section A does not specifically require filing an Incident Report, arguably DDD Policy 12.01 covers this requirement. The different types of facilities send their reports to different regional personnel who are not required to even review the reports, but merely add them to the electronic Mortality Review log. Whether the Region is permitted to conduct a fact finding review under Section D is unclear.

The portion of DDD Policy 7.05 that seems to cover most types of DDD HCBS waiver services is Section B. Section B covers adults who received services from a certified Supported Living provider, an Adult Family Home, a Companion Home, a Group Home, a Group Training Home or a SOLA program; and children who received services from a licensed Staffed Residential Home, Family Foster Home or Group Care Facility, through the Medically Intensive Children’s Program (MICP) or through a Children’s Intensive In-home Behavioral Support (CIIBS) waiver. (DDD Policy 7.05 B.) Recent revisions to Section B render portions of it unworkable. For example, Section B.3 was recently revised to a poorly worded provision that purports to designate certain reporting parties for CIIBS waivers and MICP, but could arguably be interpreted to exempt all other services from the reporting deadline.

Section C purports to make Mortality Review optional for deaths of clients receiving services under certain programs or settings, such as a paid Individual Provider or Alternative Living Program. However, since these programs/settings are not specifically listed in the 7.05 Scope, presumably 7.05 Mortality Review is not available at all for such deaths.

Regional Review

After the Quality Assurance Manager (QAM) receives a mortality report from a CRM, the QAM has 21 days to review it and scan and upload it to the electronic MR Log.

For deaths that were “unusual or unexplained” the Region “may” assemble a “mortality review team” to “conduct additional internal fact finding review and make recommendations for follow up action, as appropriate.” Section D limits the scope of Regional fact finding as follows:

- The fact finding review may identify issues in three areas:
  - Policy and procedures;
  - Clinical support practices; and
  - Medical practice.
  - Note: Specific personnel issues must be addressed separately.”
The team must review its preliminary fact finding report with an Assistant Attorney General. Once the report and recommendations are complete, the team is to add them to the MR Log. If the Regional Administrator develops an action plan, a copy must be added to the MR Log within 10 workdays of completion of the plan.

Weaknesses in Section D. Regional Review include:

- Crucial terms, “unusual or unexplained”, are not defined anywhere in DDD Policy 7.05. In the original version of 7.05, minimal guidance was given: “Unusual or unexplained deaths may be identified from the completed incident report, mortality review, media or legislative interest, and/or requests from the division director, family, agency, or provider.” (DDD Policy 7.05 D.1. as effective August 11, 2003 through April 7, 2005.) This provision was deleted from the Policy approved April 7, 2005 and all subsequent versions.

- In the original version of DDD Policy 7.05 issued August 11, 2003, this type of regional fact-finding review was mandatory, and the mortality review team was required to assess all three areas to identify issues.

- No guidance is given regarding how “specific personnel issues” may be addressed or how the Regional team is to approach issues of abuse or neglect.

- No time frame is given for completion of this review.

- No other procedures or time frames are indicated for the completion of the Regional Administrators “action plan”.

Central Office Review

The Central Office is required to review deaths falling under Sections A, B and D of 7.05. For this purpose, the Division Director will appoint a Mortality Review Team, the membership of which is specified in Section E.1. The team is required to review each report in the MR Log. The team must also review “data from the CARE System and the IR System and identify any trends or patterns”. The team will then make recommendations regarding training, policy changes or other related issues to the OQPS. The team submits annual reports to DDD executive management. It is required to complete its “review within 60 calendar days.”

The original August 11, 2003 version of DDD Policy 7.05 contained language that seemed to allow for more meaningful review. In addition to the current requirements of reviewing Mortality Review reports and data from the Incident Reporting System, the Team originally was required to review official death certificates and “review adherence to all applicable division and department policies.” Other issues that prevent a meaningful review and quality assurance process include:

- The requirement of reviewing the CARE system was only added to 7.05 in the most recent version approved January 3, 2012. This is the only reference to the CARE System identified anywhere in the DDD Policy Manual. The Source File for QIS Assurances (at slide 3) references the CARE system as an ADSA database “for information regarding individuals who have applied for and/or receive services from the Division of Developmental Disabilities (DDD). No such data were listed as reviewed by the MRT in the electronic Mortality Review Log. (pg. 20000016)

- No reference point is given from which the 60 days begins to toll. It appears this time line is an artifact from previous versions of the Policy that predate the use of an electronic MR Log when the team was
required to complete a section of the Mortality Review Form submitted by the Region. (See Attachment B.)

- There is no indication of how frequently the Mortality Review Team must meet or even whether they meet to collectively review the data at all.
- In previous versions of 7.05, the Mortality Review Team was required to report its findings to the Division Director every quarter in addition to the annual report to DDD executive management. The quarterly report was eliminated in the version approved May 1, 2009.
- Circumstances where follow up is necessary and the follow up procedure are only minimally addressed. Appended as an afterthought to Sec. E.2.e., which delineates the dangling 60 day deadline, is the bulk of the follow up procedure:
  
  e. ... The QAM will be notified of any needed follow up via email from Chief, OQPS or designee. In some instances, follow-up may be completed by the DDD Central Office Staff. The results will be entered in the DDD Mortality Review Log.

  f. The Regional QAM will provide any necessary follow up information and the results of the mortality review with (sic) the CRM and the provider.

- No reference is made to utilization of quality assurance tools such as Sigma six charts or Pareto Analysis as indicated in Waiver Application Appendix H.

Although DDD Policy 7.05 initially references DDD Policy 9.10 Client Autopsy, Policy 7.05 makes no other mention of how autopsy information must be used. The DSHS 10-331 DDD Mortality Review form has a box for the service provider to check indicating whether an autopsy was conducted, however it does not appear that the reporting service provider, the CRM/SW, or the QAM is required to attach the autopsy report to the Mortality Review Form or the MR Log. DDD Policy 9.10 limits its scope to clients residing at RHCs “including those sections certified as nursing facilities”. There does not appear to be a written autopsy procedure for clients receiving DDD services other than RHC. Policy 9.10 lists the types of deaths for which an autopsy is mandated by Washington state statute. In deaths where autopsy is not required by statute, an elective autopsy may be performed by only by request of the physicians or family/legal representative. (DDD Policy 9.10 Policy C.) The policy does not authorize anyone in the Quality Assurance hierarchy to request an elective autopsy.

This policy analysis addresses the DDD Mortality Review Policies based on the policy versions currently in effect. Both DDD Policy 7.05 and 12.01 were amended in 2012. The following flow chart represents the Policies for reporting and reviewing the deaths of waiver participants. Because the Mortality Review documents provided in response to Plaintiffs’ Requests for Documents were limited to deaths that occurred July 2011 through December, 2011, the chart reflects the policy requirements in effect during that time period. The shaded boxes on the chart reflect provisions that have changed in the present version of Policy 7.05.

Additionally, although DDD Policy 12.01 describes a process for IR follow-up and closure, it does not appear from the IR documents provided that meaningful follow up of deaths occurred under the IR system. For example, on the IR of the death of [redacted], the incident was marked “Suspicious or Unusual”, the cause of death was not yet determined and a notation indicated that the “crime unit is coming to investigate.” (pg. 20029290) However, the IR was closed 33 minutes after it was initially entered into the system and no follow up was ever documented. (pg. 20029292) Similarly, the IR for the death of [redacted] indicated that the provider was still attempting to get additional details regarding [redacted]’s death. (pg. 20029491) Nevertheless, that IR was closed a
mere 18 minutes after it was opened. (pg. 20029493) Other IRs have never been closed. (See, e.g., at pg. 20029263 and at pg. 20029263) For these reasons, that portion of Policy 12.01 is not included in the chart.

Report Serious Incidents Including Death

Failure to require and enforce timely reporting of serious incidents including death of an individual with DD while receiving public funded services is contrary to accepted standards of practice and impedes the conduct of a professionally adequate investigation and critical review of the circumstances of death. Findings that support this opinion includes the following

- DSHS policy reporting of death requirements range from “Immediately” to 14 days from date of death.
- Manner of reporting a death varies from a phone call, data entry into electronic database; electronic form, or fax.
- Delays in reporting a death by their provider suggests provider lack of appreciation for the importance of immediate notification of a death including preservation of relevant information related to the death for review and detection of any actions that caused a premature death and/or quality of care concerns that if remediated would prevent an untoward future event.

No standard set of documents received by DDD Mortality Review Part 1 Provider Report

There is no standard set of documents received by DDD Mortality Review Part 1 Provider Report.

For the 19 cases of death, June 1 – Dec. 31, 2011, in the sample studies, a DDD Mortality Review Part 1 was included in the documents provided by the defendants per plaintiff’s request. Two (2) of the 19 deaths were children deaths. Deaths of the children were reported by the DDD Mortality Review Part 1 Provider Report; however, there is no evidence that an incident report was filed with Child Protective Services (CPS) as mandated by Washington Administrative Code (WAC). There was no evidence that DDD or RCS referred these cases to CPS or the outcome of any CPS investigation.

Analysis of DDD Mortality Review Part 1 Provider Report and Documents Attached to Report (chart) found there were 88 total documents for the 19 reports provided and 307 pages for an average of 17 pages per person. This number is extremely skewed as one individual had 68 pages; number of documents per person range from 4 to 68 pages. Failure to recognize the necessity to provide basic information about a deceased individual and circumstances of death for the purpose of informing is problematic in the conduct of a meaningful review.

For example: Of the 19 cases of death, June 1 – Dec. 31, 2011, only 1 Regional Mortality Review was provided by the defendants per plaintiff’s request. The reporter quality assurance manager for region 1 led the mortality review team (MRT) “due to her experience working on the quality assurance monitoring of Children’s Staffed Residential/Foster Group Homes for the past 4 years as well her experience with performing mortality reviews and acting as the lead Quality Assurance lead”. A 3 member team (the QA Manager, an RN and a Regional Licensing Surveyor with 10 years of experience with the decedent’s facility). The stated purpose of the review was “per DDD Policy 7.05, all deaths of children in the Medically Intensive Children’s Program require a mortality review…The purpose of this review was to collaborate and identify issues with policy and procedures, clinical support practices and possible medical practices” (There is no evidence such a mortality review was completed for a deceased year old child). The report and accompanying documents included: review of
circumstances surrounding death (cause of death, chronology of events); clinical review; conclusion; and follow up—all in 68 pages.

**Lack of coordination among all related entities i.e. CPS, APS, RCS as required by WAC.**

The following examples illustrate failure to ensure coordination among all related entities i.e. CPS, APS, RCS as required by WAC:

- According to [redacted]’s DDD Mortality Review Part 1 Provider Report, “CRM notified APS on 8-16-11...Faxed CIR and [redacted] IR to APS on 8-17-11...Faxed vocational IR to APS on 8-22-11 (date received from Work Opportunities Case was assigned for investigation.)” A Central Office Incident F/U Report, 11/14/11, states RCS/APS outcome as “N/A”. There was no evidence of the outcome of the APS investigation in file received for review. The electronic DDD Mortality Review Log reported review of [redacted]’s death 11/15/11 and noted additional materials needed for review (columns AY & AZ) included “follow up by APS”.

- In the case of [redacted] (DOD 7/16/11), the DDD Incident Reporting/Central Office Incident Search produced a report that [redacted] had 3 prior incidents in 2011 (redacted) and 2 in 2010 (redacted) but the incident investigation outcomes were not noted nor copies attached to her DDD Mortality Review Part 1 Provider Report.

**Information from Electronic DDD Mortality Review Log**

Review of the Electronic DDD Mortality Review Log suggests the log is used to track DDD mortality reporting and review policies, and activities including and outside of policy requirements related to deaths in the waiver. The following is an analysis of information gathered from the Log that reported review of 19 deceased waiver participants June 1-December 31, 2012.

- 11 of the 19 (58%) individuals were female, while the remaining 8 of the 19 (42%) individuals were male.
- The ethnicity of 17 of the 19 (90%) individuals was Caucasian while the ethnicity of the remaining 2 individuals was listed as other.
- The average age of the deceased individuals is 47 years old.
- In 6 months (7/2011 – 12/2011) 19 individuals died:
  - 4 of the 19 individuals died in July, 4 died in August (2 individuals on the same day — [redacted]), 2 died in September,
  - 3 died in October,
  - 3 died in November (2 individuals on the same day — [redacted]), and
  - 3 died in December.
- There were a total of 15 providers that served the 19 deceased individuals.
  - The 4 providers that each served 2 of the deceased individuals are:
The 11 providers that each served 1 of the deceased individuals are:

- A Provider Report was received for 18 of 19 (95%) deceased individuals.
  - The average number of days from the individual’s date of death to the date the provider report was received was 11 days.
  - A 1st Review was done for 18 of the 19 (95%) deceased individuals.
  - The average number of days from the individual’s date of death to the date of the 1st review was 102 days.
  - The average number of days from the date the provider report was received to the date of the 1st review was 91 days.

- 14 of the 19 (74%) individuals were under the residence type of Supported Living, 2 of the 19 (11%) under Foster Home, and 3 of the 19 (16%) under Group Home.

- 3 (■ □ □) of the 19 (16%) individuals experienced aspiration pneumonia, 2 (■ □) of which were the cause of death and 1 (□) was a contributing factor. For another 2 (■ □) of the 19 (11%) individuals it is unknown if aspiration pneumonia was experienced, but for 1 (□) of the 2 individuals it was a contributing factor. 14 of the 19 (74%) individuals did not experience aspiration pneumonia.

- In 14 of the 19 (74%) cases, 911 was called. (This finding raises significant questions about the onset of symptoms and the emergent nature of the provider’s response to the decedents’ presenting condition.

- In 3 (■ □ □) of the 19 (16%) cases an autopsy was performed, 13 of the 19 (69%) cases an autopsy was not performed, and for 3 of the 19 cases (16%) it is unknown if an autopsy was performed. (Again, suggesting insufficient information provided at report and follow-up and also prior to MRT.)

- 11 of the 19 (58%) individuals died in their own home, 6 of the 19 (32%) died in the hospital, and 2 of the 19 (11%) died in a group home.

- A death certificate was received for 7 of the 19 (37%) individuals.

- The electronic DDD Mortality Review Log identifies sources of primary and secondary information (column CB). It is not clear who uses this information and for what purpose.
  - 8 of 19 cases reported a Certificate of Death was used as an information source. However, in another column (■ - Death Certificate Received) it reports a death certificate was received for only 7 of the 19 individuals, suggesting questionable reliability of reporting and/or data entry.
  - 3 cases reported a Provider Report was used.
  - 1 case reported a Provider Report and Case Manager were the source.
  - 2 cases reported a Mortality Review from the Agency was the information source.
  - 1 case reported a Coroner’s Death Investigation Report was used as an information source.
  - 1 case reported a Guardian was the source of additional information.
  - 1 case reported an Unofficial Death Record Abstract Working Copy Submitted by Provider as the source.
  - 1 case reported a Primary Care Dr. was used as the informant.
  - 1 of the 19 cases did not report the primary and secondary sources of information.
• Physical abuse or neglect was experienced by 2 (11%) of the 19 (11%) individuals.

• There was a total of 56 Incident Reports for the 18 of the 19 individuals.

• The log indicates the number of referrals as 14 for 11 of the 19 (58%) cases. There is no indication as to the entity receiving the referral.

• 4 of the 19 (21%) individuals were receiving care from Hospice, 2 of the 19 (11%) were receiving care from Palliative, it is unknown what type of care was being received for 7 of the 19 (37%) individuals, and for 6 of 19 (32%) individuals there was no information listed as to what type of care was being received.

• A DNR was in place for 5 of the 19 (27%) individuals, for 8 of the 19 (42%) individuals a DNR was not in place, and it was unknown if a DNR was in place for 6 of the 19 (32%) individuals.

• For 6 of the 19 (32%) individuals there was an end of life decision made, there was no end of life decision made for 11 of the 19 (58%) individuals, and there was no information for the remaining 2 of the 19 (11%) individuals.

• For the 6 individuals in which an end of life decision was made, 3 of the 6 decisions were made by a family member while the other 3 were made by the guardian.

• 6 of the 19 (32%) individuals were hospitalized, 11 (58%) were not hospitalized, for 1 (6%) individual it is unknown, and for 1 (6%) individual no information was listed.

• 15 of the 19 (79%) of the individuals were treated by a health care provider, 1 (6%) individual was not treated by the health care provider, for 2 (11%) individual it is unknown, and for 1 (6%) individual no information was listed.

• Primary causes of death for the 19 individuals:
  3 – Cardiac Arrest
  2 – Organ Failure/Aspiration Pneumonia
  2 – Pulmonary/Respiratory
  2 – Failure to Thrive
  2 – Withdrawal of Life Support
  2 – Unknown
  1 – Cancer
  1 – Heart Failure
  1 – Diabetes
  1 – Stroke
  1 – Kidney/Renal Failure
  1 – Down Syndrome and Hyperlipidemia

• There was a special mortality review (Column 41) for 1 (month old child; another child, years old did not have a special mortality review) of the 19 individuals. It is assumed that what made this review “special” was the age of the deceased. There was no reference in policy and/or procedure what warrants a “special review”.

• There was an external review for 3 of the 19 (16%) individuals. For 2 of the 3 individuals there was a report of “who is doing the external review”. The “who” in the next column of the Log was DOH for and APS for.
• The CRM has 7 days per policy 7.05 to review the report, complete section 2 at the end of the report, and send to regional QAM. According to the electronic DDD Mortality Review Log, the CRM information was timely for 15 of the 19 (79%) reports of death while 4 of the 19 (21%) reports were not timely. (Column AU)

• Only for 11 of the 19 (58%) cases reviewed did the CRM report additional review comments; for 8 of the 19 (42%) cases reviewed the CRM reported no additional comments. It is unexplainable as to why almost 50% of the cases had no additional comments, which raises the question of how much time did the CRM spend reviewing the case?

• The QAM has 21 days to review the report. The regional QA information was timely for 14 of the 19 (74%) cases reviewed, while for 4 of the 19 (21%) cases reviewed the regional QA information was not timely. For 1 (5%) case, there was no information reporting whether the QA information was timely or not.

• It was stated for 4 of the 19 cases that further material was needed, 14 of the 19 cases reviewed stated no further material was needed, and 1 case reviewed did not state whether any further materials were needed or not.

  ➢ Further Materials Needed:
  ➢ – “CRM signature on Part II, needs RCS outcome of 7/2/11 incident.”
  ➢ – “Request autopsy report (regional QA requested autopsy report from family)”
  ➢ – “RCS investigation outcome, LE?, provider report”
  ➢ – “Follow-up by APS”

Mortality Review Team

The Log noted the MRT member by name and whether they “reviewed” the case by name of the deceased. (Attachment) Analysis found:

• 12 MRT members
• 11 of 12 1st review
• # of cases reviewed per member ranged from 0-18;
• MRT meeting minutes were produced for review for only 7/20/11. Nine (9) MRT members are listed as attending this meeting and 2 listed as “Not Present”; Twenty-eight (28) names of deceased waiver participants from 10/1/10 to 6/27/11 were listed as reviewed on this one day, raising significant concern about the quality of the review. MRT activity listed:
  ➢ 19 of 28 “Ok-Close”
  ➢ 4 need additional information from last meeting-Not Complete
  ➢ 7 “total re-reviews”
  ➢ 5 “total re-reviews completed”
  ➢ 17 “total reviews”
  ➢ 14 “total reviews completed”
  ➢ 3 “total reviews need additional info”
13 Results of the review, noted by the meeting “minutes”, were rather mundane. For example: No RA signature for 3 cases; “File corrupt-upload again”; “Wait for DCFS-no file”; “Need page 2 of the investigation…”

Defendant’s counsel reported in e-mail, MRT activity is now only reported on the DDD MRT log following the July 2011.

SUMMARY AND CONCLUSIONS

My analysis of the Washington DSHS Mortality Review system found the defendant’s Mortality Review process to be so flawed it does not serve as a safeguard to protect plaintiffs’ health and safety;

The DSHS Mortality Review process does not meet the defendant’s obligation agreed to in the Settlement Agreement.

The DSHS has not fulfilled its commitments to CMS to protect the safety and improve the health of WA citizens with DDD.

The DSHS Mortality Review process does not meet the federal government’s expectation that States (Washington) have adequate safeguards to minimize unexpected deaths through Mortality review, consistent with practices for comprehensive quality assurance (QA) systems. (GAO-08-529).

The DSHS has failed to reliably operationalize critical components of a Mortality Review system. The critical component and DSHS failings:

• A dynamic uniform reporting process that ensures all deaths are immediately reported to the state level department and standard death report forms submitted within 24 hours of the death notification: No
• Screen individual death reports with standard information: No
• Standardized mortality review process (local, regional and state): No
• Medical professionals participate in the process: Yes, by assignment and according to the electronic DDD Mortality Review log. However, there are no minutes of meetings or signatures to verify participants or meeting outcome. Evidence in an e-mail exchange in the case of [redacted], between a single regional reviewer and a nurse of advanced practice illustrates the “ad hoc” use of “medical professionals”.
• External stakeholders are included in the review process: No
• State level interdisciplinary/independent of mortality review committee/board aggregates mortality data over time to identify trends: No evidence
• Direct link between mortality findings and improvement: No
• Document mortality information: No
• Produce periodic reports: Last report 2009-2010 and then limited information.
• Publicly Report findings and improvements: No

The Division of Developmental Disabilities (DDD) represented on its HCBS Waiver applications that it “has formalized waiver quality assurance processes to meet and maintain high quality standards.” (Home &
Community Based Services (HCBS) Waiver Application Appendix H.) The DDD claims that these processes assure quality in the system by requiring "continuous monitoring" of health and welfare of waiver participants and remediation “when appropriate.” My review of the Washington DSHS Quality Assurance system, specifically mortality review, found a flawed system that does not “meet and maintain high quality standards” and is not an effective safeguard to protect health and welfare. Within the 6 months studied-June 1- December 31, 2012- there was a number of preventable waiver participant deaths. In addition to the concerns I have about these avoidable deaths, the poor quality of care for other participants, whose death although expected, causes me great concern about the quality of health care coordination and provider ability to meet the health and welfare needs of Washington waiver participants.

Respectfully Submitted,

Sue A. Gant, Ph.D.

I, Sue A. Gant, PhD certify that the professional opinions rendered in my Expert Report in the matter of DUANE BOYLE, through his guardians Marion and Robert Boyle, et al., v. SUSAN N. DREYFUS, in her official capacity as the secretary of the Washington Department of Social and Health Services. issued August 6, 2012 is not contingent on the agreed to compensation of [redacted] per hour.
The following information about a sample of deceased waiver participants, June 1-December 31, 2011, was gathered from Part 1 of the DDD Mortality Review form and from documents attached to the Review form. The top of the form describes the process relative to this form as described in DDD Mortality Review Policy 7.05. The process is:

- Provider completes Part 1 of the DDD Mortality Review form upon the death of a person who was receiving services from a contracted or licensed provider or was being transported to/from services provided by contracted or licensed providers. This report must be sent to the DDD Case Resource Manager (CRM) within 14 calendar days of the person’s death.

- CRM completes review within 7 days of receiving the provider’s report (part 1) and sends to QA Program Manager.

*Bold print indicates Information from documents attached to DDD Mortality Review.

**Case #1:**

**FACTS**

**Time Line of Events**

2011
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<td>Other, Death certificate: immediate cause - failure to thrive; Mortality review: asthma, hypertension, diabetes, depression, dementia, arthritis, atherosclerotic anemia, osteoporosis, diabetic neuro</td>
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<td>Cardiac Arrest</td>
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<td>Other; Failure to thrive</td>
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**Reporting, Investigation, and Reviewing Deaths:**

**Chart Displaying Inconsistencies and Incomplete Processes in Washington DDD Policy 12.01 and 7.05**

**DDD Policy 12.01 Incident Reporting**
- Effective 9/16/2009 – 2/15/2012
- Total # Days: 1

**DDD Policy 7.05 Mortality Reviews**
- Total # Days: 102+

**Immediately Upon Death**
- Document (?) death to Central Office
- Report death to parent &/or legal representative & to coroner or medical examiner and law enforcement, as necessary

**Within 1 Hour**
- Phone call to Central Office

**Within 1 Day**
- Electronic IR

**Category A Incident:**
- Death of a RHC or SOLA client, suspicious death

**Category B Incident:**
- Death of a client (not suspicious or unusual)

**Within 1 Day**
- Electronic IR

**D. Regional Fact Finding Review For Unusual/Unexplained Deaths**
- The region may assemble a “mortality review team” to conduct an additional internal fact finding review & make recommendations for follow up action
- The regional mortality review team must review its preliminary fact finding report with an AAG
- Upon completion, the regional mortality review team forwards its report and recommendations to the OQPS
- If the RA or designee develops an action plan, a copy of this plan must be sent to the OQPS

**Central Office Mortality Review Team**
- Review all mortality review reports submitted by the regions;
- Review data from the IR System and identify any trends and/or patterns
- Make recommendations to the OQPS re: needed training, policy changes, & other related issues
- Submit an annual report to DDD executive management

**Within 60 days of receipt of Regional MR Report**
- Complete DSHS 10-331C, DDD Mortality Review Part 3: Central Office Review, documenting any recommendations and/or required follow-up by region
- OQPS forwards copy of completed report to region

**Within 21 days of receipt of report**
- QAM reviews the report, completes DSHS 10-331B, DDD Mortality Review Part 2: Regional Quality Assurance Report, and forwards the full report to the OQPS. If the death was unusual or unexplained, refer to Section D

**Within 7 days of receipt of provider’s report**
- CRM/SW reviews report, completes CRM section, and sends it to the regional QAM or designee

**14 days from death**
- The residential provider completes DSHS 10-331, DDD Mortality Review Part 1: Provider Report and sends it to the CRM

**Attachment C**

**Shaded Boxes indicate provisions which were amended in the current version of Policy 7.05**
- Case Resource Manager (CRM)
- Assistant Attorney General (AAG)
- Regional Administrator (RA)

**Quality Assurance**
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## Number of Reviews the MRT Members Were Noted For Deceased Individuals

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<th>1st Review, 2nd Review (If Required)</th>
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<td>Office Chief (QPS)</td>
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<td>Doris Barret</td>
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## Deceased Class Members 6/1/11 – 12/31/11 and # if MRT Members As Noted in DDD Mortality Tracking Chart

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