2017 Home and Community Based Services Conference

Health and Safety Practices in State HCBS Systems

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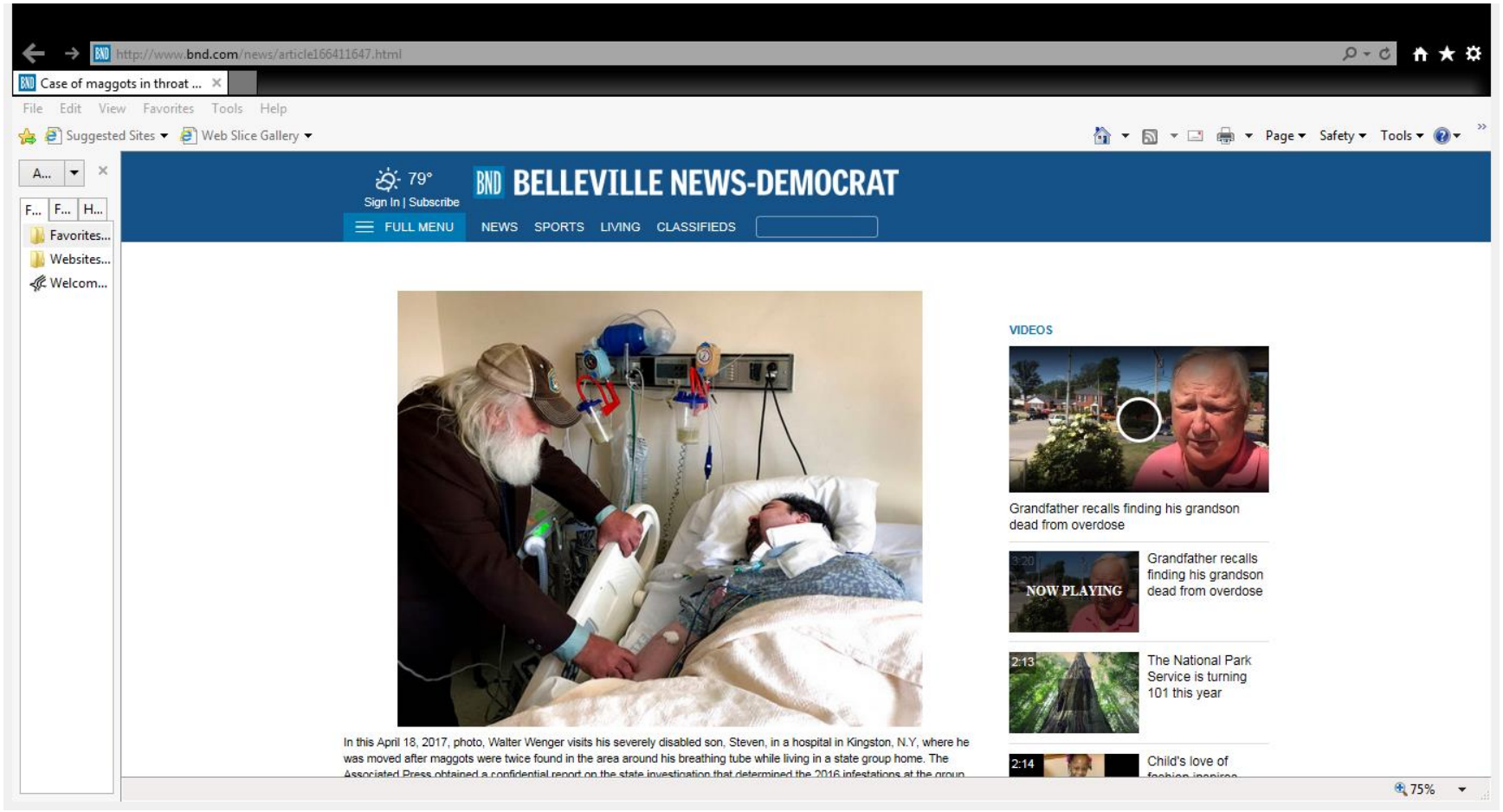
Administration for Community Living

The Need for Systemic Improvement



The Need for Systemic Improvement

- Individual with developmental disabilities are at greater risk for abuse and neglect and it occurs in a variety of settings
- Varying practices in reporting of incidences
  - Many states provide information about incidences in hospitals and nursing homes
  - Limited if any information is provided regarding incidences in state-regulated facilities, such as group homes, and not readily shared upon request

Protection and Advocacy (P&A) System

- Authorized under the Developmental Disabilities Assistance and Bill of Rights Act
- 7 P&A programs
- Independent of State agencies to protect the rights of individuals with developmental and other disabilities

P&A Authorities

- Among the P&A authorities, P&As have the authority to:
  - Monitor facilities where persons with disabilities receive services, including where they reside.
  - Conduct investigations of alleged abuse and neglect
  - Access records of individuals with developmental disabilities
- Utilizing its monitoring authority, P&A focuses on the rights of individuals, abuse and neglect, transfer and discharge procedures, along with programming and integration in the community.
- P&A does not function in the same manner as the Office of Inspector General which has the statutory and regulatory power to cite for violations and to require corrective actions.

Kentucky P&A Monitoring

- The Kentucky P&A received calls and complaints from residents and other agencies that provide services to residents living at PCHs. The complaints included:
  - Restrictions on the freedom of movement (including some residents wearing monitoring trackers, locked doors and locked fences)
  - Poor conditions of the physical building
  - Quality of food served
  - Threats of hospitalization for refusing to take medication
  - Lack of staffing
  - Alleged sexual abuse
  - Inability to access services at the local mental health center
  - Inability to transfer to another PCH

Kentucky P&A Monitoring

- As a result, the P&A used it's authority to conduct monitoring of the PCH facilities, finding that:
  - 25% of the residents reported they have been hurt at the PCH.
  - The most often reported reason for injuries was resident-to-resident fighting
  - Over 30% of the residents stated that they have witnessed another resident hurt at the PCH.

Findings from Monitoring by Kentucky P&A

- Residents stated they did not get enough to eat and were not allowed seconds at designated meal times.
- Two-thirds of the residents stated that they did not get anything else to eat if they missed the meal served because they were out of the PCH, were in their room, or simply chose not to eat at the set time.
- According to PCH regulations, a snack is supposed to be served between meals and before bedtimes; however, this is often not the case.

Louisiana P&A Review of Group Homes

- The Community Living Ombudsman Program (CLOP) at the P&A was established by Louisiana statute for the express purpose of assisting residents of privately operated group and community homes with complaints and requests regarding abuse, neglect, rights protection, services, service settings and quality of life issues.
- Based on monitoring activities, CLOP's 12 ombudsmen know which group homes in their region are significantly below standard

Findings from Investigation in Louisiana

- Facilities are often located in neighborhoods that are not safe.
- Homes systematically fail to:
  - Provide proper medical, dental, and mental health care to their residents
  - Ensure that staff are properly trained and supervised
  - Ensure that residents of the homes are treated with respect and that their privacy is maintained
  - Make sure that families are given the opportunity to participate in the lives of the residents
  - Ensure that transportation is available to allow for full integration into the community
  - Provide clean, homelike and well-maintained physical surroundings
  - Provide a healthy, adequate diet.
- Group homes often neglect the rights of residents to receive services and supports in the least restrictive environment

Development of Community Based Monitoring Systems

- The South Dakota P&A is developing a monitoring process for service providers state-wide to include:
  - Creation of a database to track monitoring activities and to decipher state-wide trends in service providers
  - Development of agency monitoring protocols that include: access authority information, monitoring checklists, possible systemic issues
  - Formation of a monitoring team within with P&A comprised of attorneys and advocates who will initiate, implement, and follow-up with any monitoring visits to service providers.
- The Massachusetts P&A developed and implemented a monitoring tool that would allow for a pro-active approach to monitoring the more than 2,300 group homes in the Commonwealth that includes a survey tool and a strategic approach to determining which facilities to monitor.

Development of Community Based Monitoring Systems

- AIDD announced funding for *Living Well-Model Approaches for Enhancing the Quality, Effectiveness and Monitoring of Home and Community Based Services for Individuals with Developmental Disabilities* to develop and test one or more model approaches of a coordinated and comprehensive system that includes two interrelated core components for enhancing and assuring the independence, integration, safety, health, and well-being of individuals living in the community: (1) Community Monitoring and (2) Community Capacity Building.
- https://www.grants.gov/web/grants/view-opportunity.html?oppId=292514

Social Security Act Section 1915(c) Medicaid Home and Community-Based Waivers:

Proposed Model Practices for Assuring Participant Health and Safety

OIG Mission Statement

Office of Inspector General's (OIG) mission is to protect the integrity of Department of Health & Human Services (HHS) programs as well as the health and welfare of program beneficiaries.

About The OIG

- OIG has a responsibility to independently report to both the Secretary of HHS and Congress.
- OIG identifies program and management problems and makes recommendations to correct them.
- OIG's work is carried out through a nationwide network of regional offices that perform audits, investigations, evaluations and other mission-related functions.

Independence

CONGRESS
WASHINGTON

HEALTH & HUMAN SERVICES
WASHINGTON

Why We Did These Audits

Congressional interest:

- Requested a review of deaths and cases of abuse of individuals with developmental disabilities residing in group homes.
- Prompted by series of articles published by the Hartford Courant and CNN regarding abuse and neglect of individuals residing in group homes.

OIG Response

- Agreed to audits in CT, MA, and NY and issue reports to the respective States.
- Expanded work to include ME.
- Reviews focused on Medicaid beneficiaries.
  - Federal criteria
    - HCBS Waiver, Appendix G, Participant Safeguards
  - Data matching

OIG Audit Objective

Determine if Medicaid State agencies complied with Federal waiver and State requirements for the reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disabilities residing in group homes.

Background

Several State departments involved with monitoring and reporting critical incidents:

- Medicaid State agency
- State service providing agency (DDS)
- State protective service agency (APS)
- Federally designate Protection and Advocacy agency (P&A)

Background

- The Social Security Act (the Act) section 1915 (c) authorized the Medicaid Home and Community-Based Services Comprehensive Supports (HCBS) waiver program.

- The HCBS waiver program allows States to:
  - Waive certain Medicaid requirements to provide care for people who might otherwise not be eligible under Medicaid.
  - Provide different services to individuals who need care and receive those services in their home or community.

- The HCBS waiver, Appendix G, *Participant Safeguards* contains the safeguards the State agencies adopt concerning the reporting and monitoring of critical incidents involving waiver participants.

Background

States frequently define critical incidents as including (but not limited to) incidents involving a severe injury that requires treatment in an emergency room or an inpatient admission.

How We Conducted Audits in CT, MA, and ME

Reviewed emergency room claims and critical incident reports for treatment of group home residents who received at least 1 of 40 diagnosis codes indicative of potential abuse or neglect:

- 400 emergency room claims in CT
- 800 emergency room claims in MA
- 100 emergency room claims and 20,000 critical incident reports in ME

❖ Some ER visits had more than one Medicaid claim for reimbursement.

Results of Audits in CT, MA, and ME

- The State agencies did not comply with Federal waiver and State requirements on reporting and monitoring critical incidents.

- State agencies did not ensure that:
  - All critical incidents were reported.
  - All critical incidents were reported correctly.
  - All reported critical incidents were recorded.
  - All critical incident data was analyzed to detect unreported incidents.

Example of an Unreported Critical Incident

- A group home did not report a critical incident involving a resident who had Down syndrome and dementia:
  - The resident wore a helmet for protection.
  - The resident required one-on-one supervision while walking.
  - The resident had an unwitnessed fall in the group home's kitchen, which was followed by a period of unconsciousness.
  - The resident was evaluated for head trauma with a CAT scan by hospital emergency room staff.

- The group home should have reported the incident immediately because these injuries met the definitions of a "critical incident" and a "severe injury."

Causes

The State agencies did not adequately safeguard Medicaid beneficiaries with developmental disabilities because the agencies lacked:

- Training to correctly identify and report critical incidents.
- Policies and procedures that established clear definitions and examples of potential abuse and neglect.
- Access to Medicaid claims data.

Recommendations

We made several recommendations to the Medicaid State agencies including:

- Develop and provide training for State and group home staff on how to identify and report critical incidents and reasonable suspicions of abuse and neglect.
- Work with DDS to update their policies and procedures to clearly define and provide examples of potential abuse and neglect that must be reported.
- Provide DDS with access to Medicaid claims data.

Related Problem: Mandated Reporters

Hospital-based mandated reporters did not report all critical incidents to appropriate State officials

- CT hospitals reported only 1 instance of potential abuse or neglect out of 300 emergency room visits reviewed.
- MA hospitals reported only 6 instances of potential abuse or neglect out of 600 emergency room visits reviewed.
- ME hospitals did not report any instances of potential abuse or neglect out of 100 emergency room visits reviewed.

Mandated Reporters: Example

- A hospital did not report a critical incident involving a group home resident who suffered a lacerated scalp and fractured cervical spine:
  - Group home staff attributed the resident's injuries to falling down a flight of stairs.
  - The resident's medical history indicated that his clavicle appeared to have been fractured in a prior incident.

- State officials indicated they would have accepted a referral for this incident if one had been made.

Results of Audit in NY

Review of Intermediate Care Facilities in New York with High Rates of Emergency Room Visits by Intellectually Disabled Medicaid Beneficiaries (A-02-14-01011)

- Issued in September 2015.
- Found the vast majority of ER visits they reviewed resulted from circumstances associated with the Medicaid beneficiaries' underlying medical conditions – not from neglect or abuse.
- Accordingly, the report contained no recommendations.

OIG Planned Work

- Will conduct similar audits in multiple States.
- Will issue roll-up report to CMS regarding audit results.
- Expanding this work to look at other settings including skilled nursing facilities.

Inter-Agency Work Group

- Created to address problems found during OIG audits.
- Provide multiple perspectives and depth of expertise across knowledge areas.

Inter-Agency Work Group

- Members include representatives from:
  - US HHS/OIG
  - US HHS/OCR
  - US HHS/ACL
  - US DOJ/CRT

Inter-Agency Work Group

Developing a set of model practices that provide States with a roadmap for how to implement better health and safety practices many of which are already required in the Act 1915(c) Medicaid HCBS Waiver, Appendix G.

Inter-Agency Work Group
Coordination and Outreach

- Coordination with CMS:
  - Provided CMS with draft of model practices for discussion.

- Outreach to national organizations:
  - National Association of States United for Aging and Disabilities
  - National Association of State Directors of Developmental Disabilities Services
  - National Association of State Mental Health Program Directors

Model Practices: A Roadmap for States

Key Goals of the Model Practices:

- Identify specific and systemic issues
- Investigate specific and systemic issues when appropriate
- Remedy specific incidents and systemic issues
- Ensure transparency to all stakeholders
- Meaningful oversight at State and Federal level

Model Practices: A Roadmap for States

Four Model Practices:

- Incident Management and Investigation Program
- Quality Assurance Program
- Mortality Review Program
- Incident Management Audit Program

Incident Management and Investigation Program

- Immediate and effective response to serious incidents.
- Timely and effective review and investigation.
- Identify and address trends and patterns.
- Timely notification of stakeholders and transparency.

Quality Assurance Program

- Oversight of service planning and delivery.
- Periodic assessment of service provider and agency performance.
- Reviews of network capacity and accessibility.
- Compliance monitoring related to Federal and programmatic requirements and outcomes.

Mortality Review Program

- Timely reporting and identification of cause and circumstances of beneficiary death.
- Where warranted corrective actions to minimize recurrence.
- Identification of mortality trends and patterns.
- Implementation of systemic responses and evaluation of their efficacy.
- Reporting mortality trends to stakeholders for transparency.

Incident Management Audit Program

- Assess timely and appropriate incident reporting and investigation.
- Assess timely and appropriate response and corrective action to serious incidents.
- Assess agency and provider actions to identify and address incident trends and patterns.

References

- *Maine Did Not Comply With Federal and State Requirements for Critical Incidents Involving Medicaid Beneficiaries With Developmental Disabilities* (August 2017, A-01-16-0001) https://oig.hhs.gov/oas/reports/region1/11600001.pdf

- *Massachusetts Did Not Comply With Federal and State Requirements for Critical Incidents Involving Developmentally Disabled Medicaid Beneficiaries* (July 2016, A-01-14-00008) https://oig.hhs.gov/oas/reports/region1/11400008.pdf

References

- *Connecticut Did Not Comply With Federal and State Requirements for Critical Incidents Involving Developmentally Disabled Medicaid Beneficiaries* (May 2016, A-01-14-00002) https://oig.hhs.gov/oas/reports/region1/11400002.pdf

- *Review of Intermediate Care Facilities in New York with High Rates of Emergency Room Visits by Intellectually Disabled Medicaid Beneficiaries* (September 2015, A-02-14-01011) https://oig.hhs.gov/oas/reports/region2/21401011.pdf

Questions?

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The U.S. Department of Health and Human Services
Office for Civil Rights

National Association of States United for Aging and Disability

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Office for Civil Rights
U.S. Department of Health and Human Services (OCR/HHS)
Who We Are

- OCR is the Department's civil rights, conscience and religious freedom, and health privacy rights law enforcement agency
- To ensure understanding of and compliance with non-discrimination and health privacy laws, OCR:
  - Investigates complaints
  - Enforces rights
  - Promulgates regulations
  - Develops policy
  - Provides technical assistance and public education

OCR/HHS Disability Nondiscrimination Activities

- OCR enforces Section 504 and ADA Title II in the areas of health care and social services.
  - OCR also enforces Section 1557 of the Affordable Care Act.
- Complaint investigations and compliance reviews
- Supporting voluntary compliance, including technical assistance and outreach
- Coalition building within HHS, other Federal agencies, and stakeholders

Section 504 of the Rehabilitation Act

- Prohibits discrimination against any qualified person with a disability in any program or activity that receives Federal financial assistance
- No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance
- Applies to recipients of Federal financial assistance and federally conducted programs

The American with Disabilities Act (ADA)

- Clear and comprehensive prohibition of discrimination on the basis of disability.

- Title II of the ADA prohibits discrimination by a “public entity,” which includes state and local government entities.

- The ADA Title II regulation requires a public entity to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” OCR is the “designated agency" to investigate complaints of discrimination on the basis of disability by State and local government health and social service agencies.

Olmstead Case

- Lois Curtis and Elaine Wilson, women experiencing co-occurring intellectual disabilities and mental health disabilities, were institutionalized in Georgia Regional Hospital in Atlanta for years after their treatment professionals determined the women would benefit from placement in the community.

- The women asserted that the State's failure to discharge them from the hospital and provide them services in a community-based program, once their treating professionals determined that such placement was appropriate, violated Title II of the ADA.

- According to the Georgia State officials, no appropriate placements existed for either woman in community settings.

Olmstead Decision

- "Unjustified isolation ... is properly regarded as discrimination based on disability.“ *Olmstead v. L.C.,* 527 U.S. 581, 597 (1999).

- Public entities are required to provide community-based services to persons with disabilities when such services are appropriate, the affected persons do not oppose community-based treatment, and the placement in a community setting can be reasonably accommodated.

Olmstead Decision (continued)

As the Supreme Court stated:

- "Institutional placement of persons who can handle and benefit from community settings **perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life**…"

- Confinement in an institution "**severely diminishes individuals' everyday life activities.**"

Most Integrated Setting

- The most integrated setting is defined as "a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." A State's failure to provide services in the most integrated setting appropriate is permitted only when the State can demonstrate that the relief sought would result in a "fundamental alteration" of the State's service system.

Olmstead Applies to People In or At-Risk of Entering an Institution

- *Olmstead* focused on individuals currently in an institution
- Subsequent cases have applied *Olmstead* to individuals at-risk of institutionalization, including those on wait lists, e.g.:
  - Needed services offered in institutions (including nursing homes) but not the community
  - Cuts in community services that would force an individual into an institution (including a nursing home)
  - Requiring individuals to first go into an institution before being eligible for community services

Examples of Olmstead OCR Complaint Resolutions

- Individual residing in 700+ bed nursing home now living in a community-based setting of his choice after OCR worked with CMS and State Medicaid agency
- Individual at risk of institutionalization from lack of sufficient attendant care services was able to stay in the community after OCR worked with the State to increase his hours of care.
- Individual in segregated employment now has a job in a day care center after OCR worked with the State to find integrated employment of her choice.

Opportunities for States

- Legacy of the ADA and the New Freedom Initiative
  - Expansion of the Money Follows the Person Program
  - Community First Choice Option
  - Balancing Incentives Program

- CMS HCBS settings rule defining “community” in Medicaid HCBS programs

- HHS Office for Civil Rights Olmstead information and investigative findings and settlements: http://www.hhs.gov/ocr/civilrights/understanding/disability/serviceolmstead/

OCR Guidance Regarding the Long Term Care Minimum Data Set

- To clarify the responsibilities of long term care facilities, in 2016, OCR issued "Guidance and Resources for Long Term Care Facilities: Using the Minimum Data Set to Facilitate Opportunities to Live in the Most Integrated Setting."

https://www.hhs.gov/sites/default/files/mds-guidance-2016.pdf?language=es.

Accessibility of Electronic and Information Technology

- Guidance for Ensuring Accessibility of Health Programs and Activities offered through Electronic and Information Technology (2016):

https://www.hhs.gov/civil-rights/for-individuals/disability/eit-guidance-bulletin/index.html

How to File a Complaint

Complete a Civil Rights Discrimination or Health Information Privacy Complaint and Consent Packet:

1. Via OCR/HHS's website: http://www.hhs.gov/ocr/office/file/index.html
2. Call and request OCR/HHS send you a complaint form packet: (800) 368-1019

Tips for Filing Complaints:

1. Be as descriptive and thorough as possible.
2. Provide as much documentary evidence as is available.
3. Share names and contact information for witnesses.
4. File within 180 days of alleged discriminatory act or health information privacy violation.

Additional OCR Resources

OCR/HHS Homepage
https://www.hhs.gov/ocr/index.html

Discrimination on the Basis of Disability
https://www.hhs.gov/civil-rights/for-individuals/disability/index.html

Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead
https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html

Sign Up for the OCR Civil Rights, Privacy and Security Listservs
https://www.hhs.gov/ocr/list-serve/index.html