Ruth Landsman

#3160

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-26-12
Baltimore, Maryland 21244-1850

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Disabled and Elderly Health Programs Group

CMCS Informational Bulletin

DATE: June 28, 2018

FROM: Timothy B. Hill, Acting Director, Center for Medicaid and CHIP Services

SUBJECT: Health and Welfare of Home and Community Based Services (HCBS) Waiver Recipients

Introduction

The Center for Medicaid and CHIP Services (CMCS) is releasing this Informational Bulletin to address the issues outlined in the January 17, 2018 report titled "Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight"[1] ("the Joint Report") developed by three agencies of the Department of Health and Human Services: Administration for Community Living (ACL), Office for Civil Rights (OCR), and Office of Inspector General (OIG). CMS takes the health and welfare of individuals receiving Medicaid-funded Home and Community-Based Services (HCBS) very seriously, and we are providing the following CMS perspective on the issues raised in the Joint Report for state and stakeholder awareness.

This Bulletin addresses one of the three suggestions the Joint Report made to CMS: *encourage states to implement compliance oversight programs for group homes, such as the Model Practices, and regularly report to CMS.* Information contained here is consistent with the March 12, 2014 Informational Bulletin titled, "Modifications to Quality Measures and Reporting in § 1915(c) Home and Community-Based Waivers[2]" and will not supplant and/or rescind that document. This release will be the first in a series on this topic of health and welfare. CMS intends to issue future guidance highlighting promising practices in effectuating the suggestions contained in the Joint Report, along with proposed performance metrics for evaluating the health and welfare of individuals receiving HCBS waiver services.

The Joint Report compiled individual audits across four states conducted by OIG to determine how states were ensuring the health and welfare of individuals with developmental disabilities

[1] https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf
[2] https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/downloads/3-cmcs-quality-memo-narrative.pdf

residing in group homes[3]. In addition, proposed Model Practices for components of a robust oversight framework were identified in the Joint Report, including State Incident Management and Investigation, Incident Management Audits, State Mortality Reviews, and State Quality Assurance. Each of these is addressed below.

At the outset, CMS acknowledges that ensuring high quality HCBS to Medicaid beneficiaries is a shared goal among our state partners, provider communities, beneficiaries and their families and caregivers, and other stakeholders. Medicaid-funded HCBS play a critical role in facilitating beneficiary independence and community participation. The information contained here is meant to reaffirm CMS' commitment to provide necessary technical assistance to states in the development, implementation, and improvement of a quality oversight program. We encourage states to review this information as they look to strengthen their quality assurance system.

Incident Management and Investigation

A strong system of quality oversight utilizes a framework that defines and captures information on potential instances of abuse, neglect, or exploitation and emphasizes the importance of awareness and identification of critical incidents. There is no standard federally defined term for "critical incident" that outlines the scope of reportable incidents, leading to variation across states in the Medicaid program, and sometimes even across programs within the same state. Based on information contained in the Joint Report, along with the Agency's review of states' submitted HCBS waiver applications, CMS strongly encourages states to define critical incidents to, at a minimum, include unexpected deaths and broadly defined allegations of physical, psychological, emotional, verbal and sexual abuse, neglect, and exploitation. See pages A-iv and A-v of the Joint Report for a more comprehensive list of suggested reportable incidents. Awareness of critical incidents is the first step states require to determine whether an investigation or potential changes to the provision of services is necessary.

CMS supports the information contained in Appendix A of the Joint Report, titled "Model Practices for State Incident Management and Investigation" and finds it consistent with the expectations in the March 12, 2014 Informational Bulletin. Ensuring that the right information is generated at the provider/individual level and communicated to the state provides the basis for state-conducted review of data for timely trend analysis, investigations of specific incidents consistent with waiver materials and state policies, procedures and requirements, as well as implementation of any resulting corrective actions. The identification of emerging trends of concern is an important analysis for states to perform to determine whether systemic controls are in place or need improvement to prevent future incidents of abuse, neglect, and exploitation.

Reporting critical incidents plays an important role in a quality oversight program, and we believe that it is necessary to ensure that an approach to incident management is not perceived as punitive, but instead as an opportunity to help make quality oversight systems stronger. There is

[3] While there is no standard definition of a "group home," they tend to be congregate residential settings of various sizes in which individuals with a unifying characteristic or diagnosis – such as a developmental disability, mental illness, etc. - receive services.

a balance that CMS and the states must strike to ensure that we are encouraging, not inadvertently discouraging, providers and other stakeholders to report and resolve critical incidents and to be active participants in ongoing quality improvement efforts.

Incident Management Audits

States are encouraged to conduct audits of their incident management systems to ensure that information on all occurrences meeting the state's definition of a critical incident are reported appropriately and lead to investigations to determine the need for any corrective actions. This is consistent with the instructions for administrative oversight in the section 1915(c) Instructions, Technical Guide and Review Criteria. The information contained in Appendix B of the Joint Report, titled "Model Practices for Incident Management Audits," provides a good resource for how these audits could be conducted. While the OIG audits focused on incidents that led to hospital emergency department visits, CMS recognizes that not all emergency department utilization is due to abuse, neglect, or exploitation; likewise, not all incidents of abuse, neglect, or exploitation result in emergency department visits. States should implement an auditing protocol that captures all incidents that are relevant to the state's definitions of critical incidents, and reflects all locations in which those incidents could occur.

In response to the Joint Report's suggestions to review Medicaid claims data as part of incident management audits, CMS acknowledges that potential time lags between service provision and claims submission may make this type of review most appropriate on a retrospective basis to identify where incidents have been reported and/or not reported consistent with the emergency department visits audit, trends, and potential system improvement strategies.

Mortality Reviews

CMS agrees with the role that reviews of beneficiary deaths can have in a state's overall quality oversight system. CMS also agrees with the information contained in Appendix C of the Joint Report, titled "Model Practices for State Mortality Reviews". The distinction on page C-ii of the Joint Report is important: while states should require a preliminary review of all beneficiary deaths, investigations should focus on deaths that are determined to be "unusual, suspicious, sudden and unexpected, or potentially preventable, including all deaths alleged or suspected to be associated with neglect, abuse, or criminal acts." CMS recognizes that state Medicaid agencies and state operating agencies cannot mandate that autopsies be performed. States are encouraged to establish relationships with relevant agencies performing autopsies to maximize the likelihood of their performance upon state request. CMS notes the significance of mortality reviews in identifying trends in critical incidents and implementing systemic interventions that help protect against such critical incidents.

Quality Assurance

Appendix D of the Joint Report, titled "Model Practices for State Quality Assurance," brings information discussed earlier in the Report together into a comprehensive quality oversight

strategy. CMS, working with State Associations and representative states, agreed that this was a critical need in the state's Quality System for Health and Welfare issues and communicated that in the 2014 Informational Bulletin. CMS supports the infrastructure described in Appendix D of the Joint Report, including the focus on ensuring the provision of person-centered planning and services, and the inclusion of beneficiaries and other stakeholders in the development and implementation of a HCBS quality oversight program.

Ensuring the transparency of information associated with HCBS quality oversight is a critical step in fully utilizing the perspectives of such a wide array of stakeholders. States are encouraged to establish regular and clear communications with stakeholders, including individuals receiving or on a waiting list for HCBS. All reports generated as part of a state's HCBS quality assurance program should be published online and made available (in plain English and other relevant languages) to stakeholders. Finally, states are encouraged to identify ways to close feedback loops with individuals who are experiencing difficulties in receiving HCBS.

Next Steps

CMS encourages states, providers, and other stakeholders to become familiar with the Model Practices contained in the Joint Report. They represent sound recommendations in the implementation of good quality management programs and are consistent with the March 12, 2014 Informational Bulletin. In upcoming guidance, CMS intends to highlight examples of how these recommendations are being successfully utilized in the delivery of HCBS. CMS remains available to provide technical assistance on quality oversight to states under the various HCBS authorities.

CMS notes the potential availability of enhanced federal matching funds for state activities to implement the Model Practices described in the Joint Report. Enhanced federal administrative match of 75% may be available for these activities if they are part of a medical and utilization review performed by certain utilization and quality control peer review organizations under subsections (b)(6)(i) and (b)(10) of 42 CFR 433.15. CMS encourages states to enlist the assistance of qualified entities in this important work. States may contact their CMS Regional Office to discuss the possibility of enhanced administrative matching and the development of an administrative claiming plan for CMS review and approval. Likewise, states may also contact their Regional Office to determine the availability of 90% federal match for expenditures related to development of an automated data processing (ADP) system through the advanced planning document (APD) process under 42 CFR 433.112(a).

CMS looks forward to working with states in continued efforts to assist Medicaid beneficiaries in maintaining community integration and receiving quality services.

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Disclaimer

- The information presented today is intended to increase knowledge in support of individuals with intellectual and developmental disabilities
- The information is not intended to replace recommendations or instructions from an individual's health care practitioner

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Objectives

- Review four common medical conditions that are associated with preventable health complications and death
- Define each condition and review:
  - Complications
  - Symptoms
  - Causes and risk factors
  - Treatment and prevention
- Discuss planning for:
  - Risk mitigation
  - Staff education
  - Quality assurance

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What are the Fatal Four?

- Four major health concerns seen frequently in individuals with intellectual and developmental disabilities which if untreated can progress to serious illness or death.
- These conditions are often preventable or at least able to be managed effectively with attentive care.
- Deaths associated with these conditions are often preventable deaths

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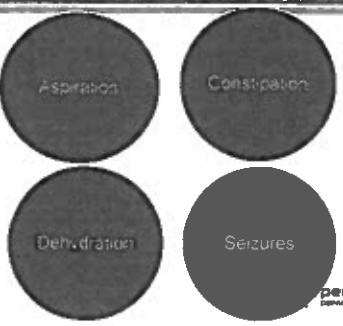
What are the Fatal Four?



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Aspiration

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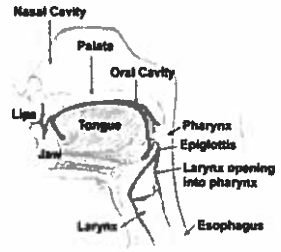
Anatomy



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Definitions and Complications

- **Aspiration:** When fluid, food, saliva or medication enters the lungs
- Aspiration can lead to refusal to eat, weight loss, poor nutrition, wheezing, difficulty breathing, hypoxia, and/or pneumonia which can cause death.
- **Choking:** When food or other items become lodged in the back of the throat.
- Choking can lead to a blockage in the airway, preventing oxygen from entering the lungs and the blood stream.
- This can quickly lead to irreversible brain damage and death.

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Signs and Symptoms

Aspiration

- Coughing or excessive drooling with eating or drinking
- Difficulty breathing or shortness of breath
- Wheezing
- Statement such as "food is getting stuck"
- Frequent throat clearing
- Eating too fast or packing the mouth

Choking

- Anxious or agitated state
- Reddened face
- Difficulty or noisy breathing
- Severe coughing or gagging
- Hands to throat
- Not able to talk
- Not able to breath
- Skin turning gray or blue
- Loss of consciousness

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Aspiration/Choking

Causes

- Difficulty swallowing - dysphagia
- Gastroesophageal reflux disease (GERD)
- Eating too rapidly
- Being fed too quickly
- Improper positioning
- Improper consistency or texture of food/liquids

Risk Factors

- Dysphagia diagnosis
- Medical disorders, including neurological
- Low muscle tone
- Polypharmacy
- GERD, esophageal strictures, feeding tubes
- Decayed or missing teeth, ill-fitting dentures
- History of pneumonia

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Aspiration/Choking

Treatment

- Identify symptoms of aspiration or choking
- Notify heath care practitioner for appropriate treatment options
- Treatment of complications of aspiration
- If individual is choking
  - Initiate first aid
  - If individual becomes unresponsive, move him/her to the floor and begin CPR
  - **THIS IS AN EMERGENCY: WHEN CALLING 911, CALL IMMEDIATELY! DO NOT SEEK SUPERVISORY APPROVAL!**

Prevention

- Staff training for identification, documentation, modified food and drink consistency
- Notify health care practitioner, so appropriate diagnosis can be made
- Notify health care practitioner of every choking event
- Review and follow care plans
  - Supervision and assistance per orders
  - Always follow the prescribed diet
  - Prepare food as instructed
  - Avoid foods that were identified to increase risk
  - Dentures are securely in place and oral hygiene is completed per ISP.

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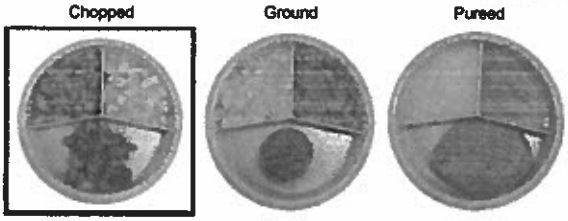
Food Consistencies

Chopped | Ground | Pureed



http://www.dbhds.virginia.gov/library/quality%20risk%20management/qrm-standard%20guidance%20for%20food.pdf

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Constipation

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Constipation

- Definition
  - Infrequent, hard, or hard to pass stool
  - Infrequent is often defined as fewer than three bowel movements a week
  - Normal frequency of bowel movements vary from person to person
- Complications
  - Discomfort/pain
  - Behavioral changes
  - Hemorrhoids (swollen blood vessels)
  - Anal fissures (small tears and bleeding)
  - Rectal prolapse (intestinal lining pushing through anus)
  - Fecal impaction (stool blocks the colon/rectum)
  - Bowel obstruction (complete blockage and a medical emergency)
  - Bowel perforation
  - Death

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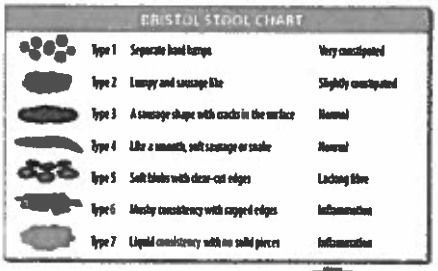
Constipation



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Constipation Symptoms

- Hard and dry feces
- Hard, protruding abdomen
- Bloating and complaints of stomach pain
- Vomiting digested food that smells like feces
- Anorexia (loss of appetite)
- Behavioral outbursts
- Fever
- Overflow incontinence

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Constipation

Causes
- Inadequate fluid intake
- Inadequate fiber intake
- Uncoordinated muscle contractions
- Immobility
- Inactivity
- Medications
  - Iron supplements
  - Calcium supplements
- Pica (eating non-food substances)

Risk Factors
- Cerebral palsy
- Cystic fibrosis
- Muscular dystrophy
- Spinal cord injury
- Neurological damage
- Down syndrome
- Illness or injury
- Poor diet
- Polypharmacy

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Constipation

Treatment
- Juice (apple/prune)
- Suppositories
- Laxatives
- Stool softeners
- Enema
- Disimpaction (removing stool)
- Nasogastric tube

Prevention
- Track bowel movements
- Adequate fluid intake
- Adequate fiber intake
- Regular exercise
- Probiotic agents
- Bulking agents
- Laxatives

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Dehydration

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Dehydration Definitions/Complications

- Loss of the amount of water in the body and may have alteration in electrolyte levels
  - Sodium, potassium, calcium, chloride, magnesium
- Complication can be serious and include
  - Constipation
  - Heat injury
  - Acute kidney injury/kidney failure
  - Seizure from abnormal electrolyte levels/cerebral edema
  - Loss of consciousness/coma
  - Loss of blood volume or shock which can lead to death

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Dehydration Symptoms

Mild/Moderate Dehydration
- Dry mouth
- Dry eyes
- Increased thirst
- Dark concentrated urine
- Decrease urine volume
- Muscle weakness
- Headache
- Dizziness

Severe Dehydration
- Extreme thirst
- Confusion
- Lethargy
- Sunken eyes
- No sweating
- Low blood pressure
- Coma

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Dehydration

Causes
- Decreased intake of fluids
- Increased loss of fluids

Risk factors
- Difficulty swallowing
- Limited mobility
- Poor communication
- Poor thirst recognition
- Certain medications or medical illnesses
- Heat or humidity exposure

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Dehydration

Treatment
- Fluid and electrolyte replacement
- IV fluids for severe dehydration
- Hospitalization for symptoms of circulatory collapse
- Potassium supplements
- Treat underlying cause

Prevention
- Drink plenty of fluids
- Increase fruits and vegetables
- Increase fluid intake with
  - Presence of vomiting and diarrhea
  - Strenuous exercise
  - Heat exposure
  - Other illnesses or certain medications
- Do not ignore your thirst
- Avoid caffeine and alcohol

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Seizures

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Seizures Definition/Complications

- Abnormal, unregulated electrical activity in the brain resulting in involuntary alterations in behavior or physical symptoms.
- Complications:
  - SUDEP (Sudden unexpected death in epilepsy)
  - Falls with injury
  - Other traumatic injuries
  - Aspiration
  - Automobile accidents
  - Tongue, lip or cheek injuries related to biting
  - Status epilepticus

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Seizures - Symptoms

- The symptoms of a seizure will depend on which area of the brain is affected. Symptoms vary with individuals common symptoms include:
  - Unresponsive or staring
  - Fluttering of eyes or rolling eyes up or in a specific direction
  - Lip smacking
  - Muscle spasms- on one side or full body
  - Loss of bladder or bowel
  - Numbness or tingling in extremities
  - Hearing or smelling things that are not there

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Seizures

Causes

- Missing doses of anti-seizure medication
- Dehydration
- High fever
- Too high or low blood sugar
- Sensory stimuli (strobe lights, video games)
- Polypharmacy
- Severe constipation

Risk Factors

- Neurological disorders
- Cerebral palsy
- Down syndrome
- Traumatic brain injury
- Stroke
- Tuberous sclerosis
- Autism
- Infections
- Drugs or toxins
- Brain tumors
- Diabetes

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Seizures - Treatment

- If seizure lasts longer than 5 minutes: Call 911
- If repeat seizure without return to baseline: Call 911
- Ensure the individual's safety during seizure activity
- Documentation that includes: seizure activity, duration and individual's response
- Anti-seizure medications
- Elimination of cause
- Vagus nerve stimulation
- Dietary treatment
- Neurosurgical intervention

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Seizures Prevention

- Most seizure disorders cannot be prevented, effective management is key
  - Compliance with medication and monitoring
  - Avoid situations which trigger seizure
  - Avoidance of constipation
  - Avoidance of dehydration
  - Early treatment of infection and fevers
  - Reduce possible complications (do not drive or swim alone)
  - Refrain from use of recreational drugs

Actions to Mitigate the Risk to Individuals

- Review current and/or develop policies and procedures that:
  - Address measures to identify individuals at risk
  - Establish precautions to minimize or eliminate the causes
  - Ensure appropriate documentation and accuracy of records
  - Establish processes for emergency response and calling 911

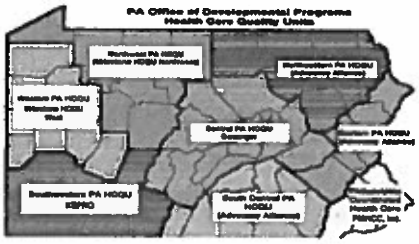
Staff Education

- Establish education plan for staff
  - Contains information on identifying the at risk individuals
  - Reviews signs and symptoms
  - Ensures staff competency with all aspects of the individual's care plans
    - Medical evaluations/recommendations, assessments, ISPs, and any other treatment plans used
  - Competency with emergency response

Quality Assurance

- Establish Quality Initiatives program
  - Monitors compliance
  - Establishes policies to address non-compliance
  - Identifies opportunities for improvement
  - Addresses reporting and investigation of incidents

Additional Information and Technical Assistance



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Independent Regulatory Review Commission

October 18, 2018

Regulation #14-540: Home and Community-Based Supports and Licensing information

My name is Ruth Landsman and will I am the parent of a young man receiving waiver services in unlicensed settings, I am the guardian of a young lady receiving licensed residential services, and I am an advocate who on average speaks to more than 500 families through the year in addition to email and listserv contacts where concerns and complaints are shared by families. I appreciate the opportunity to present these comments today in addition to what I submitted earlier this week. When I conclude I will be giving you copies of two recent training power points the state has used with providers pointing out the importance of some of the areas of concern which may become more difficult to track if the proposed changes are approved. I will also be providing to you a CMS Informational Bulletin concerning health and Safety concerns for waiver recipients.

While I appreciate the efforts made by the department to include a large group of stakeholders in the development and modifications of these regulations, I feel that the changes which have been made are heavily weighted toward unburdening the provider community who has to implement the regulations. As you review the comments that have come in I am sure you noticed that the providers who commented still complained about rate issues and the burdens of the incident management system. What about the people effected? At the same time, advocates and family members worry about the quality of services and the hazards their family members are or could be facing if the proposed changes go into place. Even the advocacy groups who supported the approval of the regulations remaining concerns about a number of areas included in the regulations under consideration. Temple University Institute on Disability had a list of 8 areas needing to be 'revisited' including: Training, residential program size, individual plan process, day program size limitations, incident data analysis, transition planning, quality management, and support broker compliance. This touch on nearly all areas of the regulations!

While their hope was that the department would issue guidance which would address these remaining issues it would be a much stronger message if the regulations included all of these areas. Although these regulations mark an improvement over the current regulations the fact that the department has not issued such guidance for improvements in the years since the 5100 were enacted without going through the IRRC process under Act 22, I have little hope that this will occur in any meaningful way and such protections must be included in the regulations before they are approved..

While the increase in the areas that would require investigation mark an improvement in the incident management system the removal of emergency room visit tracking is a major shortfall. ODP acknowledges at section 6100.401 the removal of emergency room visits would significantly lower the number of incidents which need to be reported and therefore investigated and reviewed. In Philadelphia alone over the past year there were 2500 emergency room visits documented by incident reports and no way to know how many went unreported or how many visits to urgent care centers were made by waiver recipients instead of ER visits. Info regarding ER visits can yield valuable information by reviewing them to make sure they are properly categorized and that they do not reflect a failure to provide regular medical care and visits with primary care physicians. The department and administrative entities cannot keep up with the review of these large numbers of incidents so they are removing this major category. In other terms it would be like the police removing stop signs and traffic signals because they couldn't keep up with the ticket writing for the violations they witnessed!

One need look no further than the horrendous situations that occurred at Blossom in Philadelphia in the latter part of last year to underscore the failure of the state and the administrative entity to oversee and hold accountable and improve the circumstances residents were encountering to view the total failure of accountability and assurances of health and safety of individuals served by this provider. The proposed changes would only intensify situations like this getting out of control before any attention was paid to them. The changes in the time frames to report incidents and notify families or guardians will further impact negatively the health and safety of waiver participants. Unfortunately, there are many potentially similar situations likely to occur (with hopefully less disastrous outcomes) due to the lack of accountability efforts by the state. Efforts need to be focused on the proper reporting of all incidents in the HCSIS system and to families with state oversight of timely review and investigation as well as interventions, retraining, and sanctions where necessary. These regulations do not in any way address this serious accountability issue and they must!

The reduction of training requirements even though they are minimum requirements, at a time when far greater training is actually necessary and required is another serious concern. Following the recent requirement for experience of CEO's being hired for agencies providing residential services, it is especially troubling that their training requirement is half of direct care staff! The state consistently responded to comments about the training requirements by saying that the rates took into account the level of training. While this may be true it shows that the state has looked at making these changes without these regulations in place. The department claimed that without these regulations in place they run the risk of losing massive federal funding for the waivers. Their commitments to CMS should and must be honored with or without these regulations and can be enforced through the oversight the state has as the single Medicaid agency. We all have a vested interest whether we are family members, advocates, legislators, bureaucrats, providers, or just taxpayers. The choice of the IRRC can be looked at simply asked whether your priority is the burdens on the system established and being paid to provide health and safety to some of the most vulnerable citizens of the Commonwealth or the health and safety of those vulnerable citizens! I hope that this commission makes the right choice.

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Residential Provider Meeting
Office of Developmental Programs

July - August 2018

Why We Are Meeting

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To dialogue with providers about improvements in residential services based on recent developments and advisory publications.

- Publication by HHS, OIG, ACL and OCR - "Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight";
- What we've learned from the Federal OIG investigation of Pennsylvania's incident management system;
- Analysis of incidents of deaths, serious injuries, neglect;
- Analysis of licensing actions;
- Findings from the root cause analysis of residential licensing action.

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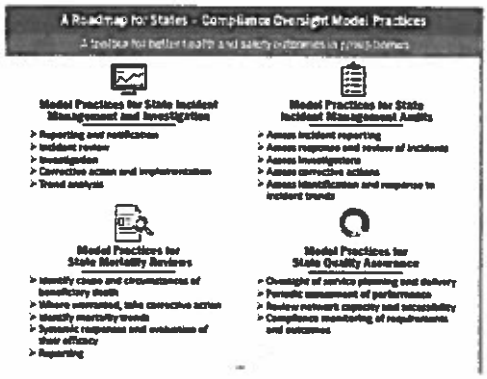

Analysis of Incidents

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Choking with Eating

- Between January 1, 2016 and March 31, 2018, ODP received 700 incident reports where people experienced a choking episode while eating. On average, 13 "choking while eating" incidents are reported each week.
- Fourteen (14) participants who experienced a choking episode while eating died within 7 days of the event as a direct or indirect result of the choking event.
- 201 of the above incidents were investigated by an ODP-Certified Investigator. Investigation confirmed that neglect contributed to the choking episode in 85 cases.

Analysis of Incidents

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- Between January 2015 and December 2016, 452 distinct participants receiving services in a 6400 Community Home presented at an emergency room at least once with at least one of the above disorders. The numbers below show the number of emergency room visits by disorder (Note: numbers will not sum to 452 as some participants presented with more than one disorder):
- Bowel Obstruction / Constipation - 124 participants
- Aspiration – 23 participants
- Dehydration – 40 participants
- Seizure – 158 participants

Qualitative Analysis of Incidents

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Qualitative analysis of incidents and regulatory violations found five reoccurring conditions that consistently resulted in or contributed to unexpected death in 6400-licensed residential settings:

- **A documented history of at least one similar event.** Post-event analysis finds that participants who died as a result of an event (e.g. choking) had at least one prior event of a similar nature.
  - Example, participants with choking fatalities had at least one choking event before the event that led to death. The event usually does not have health consequences that are immediately apparent (such as the need for hospitalization), which suggests that such events are not recognized as sentinel events.
- **Previous recommendations by medical professionals were not acted upon.** Post-event analysis finds that participants who died as a result of an event or serious medical condition finds evidence that specialized evaluation or treatment was recommended at some point in the past but not acted upon.
  - Example: records of multiple participants who died as a result of wandering behavior contained examination results showing the onset or worsening of dementia.

Qualitative Analysis of Incidents

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- **Staff caring for the participant had little-to-no experience working in the home or with the participant.** Staff on duty at the time of fatalities usually did not work in the home before the event, or only did so on occasion, and did not have any experience supporting the participant prior to the day the event occurred.
- **Staff caring for the participant were not trained on the participants' needs.** Investigation of deaths consistently finds that staff were not provided with a copy of the ISP and were not trained to meet the participant's specific needs. To the extent that staff are familiar with the person's needs, it is usually via word-of-mouth, i.e. another staff person provided some sort of nonspecific guidance.
- **Inconsistencies in participants' care plans.** Medical and support records of participants who died are frequently unclear or inconsistent. In cases of choking fatalities, terms such as "pureed," "soft," "mechanically soft," etc. are used interchangeably and supervision needs are vague (e.g. "needs supervision while eating," "needs to be reminded to chew slowly," etc.) or in conflict at different points (e.g. "Jane is independent at mealtimes / Jane needs supervision while eating / Jane cannot have lunchmeat").

High-Risk Regulatory Violations

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ODP has identified four regulations that pose the highest risk of harm:

§ 6400.16. Abuse / § 6400.33(a) - Abuse of an individual is prohibited / an individual may not be neglected, abused, mistreated or subjected to corporal punishment.

§ 6400.62(a) - Poisonous materials shall be kept locked or made inaccessible to individuals who cannot safely use them.

§ 6400.68(b) - Hot water temperatures in bathtubs and showers may not exceed 120° F.

- 139 violations for hot water above the allowable maximum.
- For most adults, a second-degree burn will occur after 24 seconds of exposure to water that is 130° F; in 54 cases, the water temperature was 130° F or higher.
- For most adults, a second-degree burn will occur after 5 seconds of exposure to water that is 140° F; in 11 cases, water temperature exceeded 140° F.

§ 6400.144. - Health services, such as medical, nursing, pharmaceutical, dental, dietary and psychological services that are planned or prescribed for the individual shall be arranged for or provided.

Our Core Customers

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- Behavioral health
  - Trauma
  - Mood/Anxiety Disorder
  - Psychotic Disorder
  - Neurodiversity/Autism Spectrum
- Physical disabilities
  - Mobility Impairment
  - Dysphagia – Swallowing difficulties
  - Neurologic – low muscle tone, seizures
- Health Conditions
  - Diabetes
  - Respiratory
  - Heart Disease
  - Age related conditions – falls, dementia, changes in metabolism

The Fatal Four – Dr. Greg Cherpes

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Health Risks – the Fatal Four

- Constipation,
- Aspiration,
- Dehydration,
- Epilepsy

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Service Definition
Residential Habilitation

Residential Habilitation – Principles

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- **Every participant has the capacity to engage in lifelong learning.** Participants will acquire, maintain, or improve skills necessary to live more independently and to participate meaningfully in community life.
- The type and amount of assistance, support and guidance are informed by the
  - Person-centered planning processes
  - Personal preferences
  - Personal desired outcomes
- **Residential Habilitation services are the primary residence of the participant and as such, it is his or her home.**
- **Respect for personal routines, rhythms, rights, independence, privacy and personalization are intrinsic to the service as is access to experiences and opportunities for personal growth.**

Service Definition - Scope of Service

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1. **Activities of daily living** - personal grooming and hygiene, dressing, making meals and maintaining a clean environment.

2. **Develop and maintain positive interactions and relationships** with residents of the home, sharing meals and activities.

3. **Learn and develop practices that promote health and wellness**

   Meal planning, regular exercise, carrying through prescribed therapies and exercises, awareness and avoidance of risk including environmental risks, exploitation or abuse; responding to emergencies in the home such as fire or injury, knowing how and when to seek assistance.

Service Definition (Continued)

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4. **Manage/participate in the management of his/her medical care**

   Scheduling and attending medical appointments, filling prescriptions and self-administration of medications, and keeping health logs and records.

5. **Manage his/her mental health and emotional wellness**

   Self-management of emotions such as disappointment, frustration, anxiety, anger, and depression; applying trauma informed care principles and practices and accessing mental health services.

   The service should include: a comprehensive behavior assessment; design, development and updates to a behavior support plan that includes positive practices and least restrictive interventions; development of a Crisis Intervention Plan; and implementation of the behavior support plan, Crisis Intervention Plan and/or the skill building plan which involve collecting and recording the data necessary to evaluate progress and the need for plan revisions.

Service Definition (Continued)

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6. **Participate in the development and implementation of the service plan** and direct the person-centered planning process including identifying who should attend and what the desired outcomes are.

7. **Make decisions** including identifying options/choices and evaluating options/choices against a set of personal preferences and desired outcomes, including assistance with identifying supports available within the community.

8. **Achieve financial stability** through managing personal resources, general banking and balancing accounts, record keeping and managing savings accounts and programs such as ABLE accounts.

Service Definition (Continued)

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9. **Communicate** with providers, caregivers, family members, friends and others face-to-face and through the use of the telephone, correspondence, the internet, and social media. The service may require knowledge and use of sign language or interpretation for individuals whose primary language is not English.

10. **Use a range of transportation options** including buses, trains, cab services, driving, and joining car pools, etc. The Residential Habilitation provider is responsible for providing transportation to activities related to health, community involvement, and the service plan. The Residential Habilitation provider is not responsible for transportation for which another provider is responsible.

11. **Develop and manage relationships in the home** as appropriate, share responsibilities for routines such as preparing meals, eating together, carrying out routine home maintenance such as light cleaning, planning and scheduling shared recreational activities and other typical household routines, resolving differences and negotiating solutions.

Service Definition (Continued)

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12. Develop and maintain relationships with members of the broader community and to manage problematic relationships.

13. Exercise rights as a citizen and fulfill his or her civic responsibilities such as voting and serving on juries; attending public community meetings; to participate in community projects and events with volunteer associations and groups; to serve on public and private boards, advisory groups, and commissions, as well as develop confidence and skills to enhance their contributions to the community.

14. Develop personal interests, such as hobbies, appreciation of music, and other experiences the participant enjoys or may wish to discover.

15. Participate in preferred activities of community life such as shopping, going to restaurants, museums, movies, concerts, dances and faith based services.

Integration of Behavioral Support

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Inclusion of behavioral support professionals in residential provider agency organization strengthens provider's ability to build internal capacity.

- Behavioral support interventions/plans must be developed in the context of the entire home and all of the residents living in the home.
- Behavioral support professionals must be members of the entire team serving the home.
- As an internal resource, behavioral support professionals can be available immediately without the need to request a service plan modification, predict the number of units needed and obtain authorization.

Behavioral Support

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- The residential services provider must have behavioral specialists available (direct, contracted or in a consulting capacity) who, as part of the residential service, complete assessments, develop and update Behavioral Support Plans and Crisis Intervention Plans and train other agency staff.
- The behavioral specialist ensures behavioral support provided to the participant includes positive practices and least restrictive interventions and does not include chemical or mechanical restraints, and that physical restraints are used only in emergencies and not as planned support strategies.
- Behavioral Support: comprehensive assessment, development of strategies to support participant, provision of interventions and training to participants, staff, parents, and caregivers. Services must be required to meet current needs of the participant, as documented and authorized in the service plan.

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ODP Improvement Strategies

ODP Improvement Strategies

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- Service definition and rates allow for hiring clinical professionals
- HCQUs training and technical assistance including on the Fatal Four
- Instituting, through county agreements, a county routine risk assessment in conjunction with support coordination organizations.
- Licensing Standards of Practice for licensing staff
- Interpretive licensing guidelines that target at risk residents
- Developed mortality review process
- Modifications to Speech Language Therapy service to allow for swallowing assessments, education and treatment

Speech and Language Therapy

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- Services provided by a licensed and American Speech-Language-Hearing Association (ASHA) certified speech-language pathologist to participants with a wide variety of speech, language, and swallowing differences and disorders. Communication includes speech production and fluency, language, cognition, voice, resonance, and hearing. Swallowing includes all aspects of swallowing, including related feeding behaviors. Speech and language therapy includes:
  - Counseling participants, families and caregivers regarding acceptance, adaptation, and decision making about communication, feeding and swallowing, and related disorders.
  - Prevention and wellness activities that are geared toward reducing the incidence of a new disorder or disease, identifying disorders at an early stage, and decreasing the severity or impact of a disability associated with an existing disorder or disease.
  - Screening participants for possible communication, hearing, and/or feeding and swallowing disorders.
  - Assessing communication, speech, language and swallowing disorders. The assessment process includes evaluation of body function, structure, activity and participation, within the context of environmental and personal factors.
  - Developing and implementing treatment to address the presenting symptoms or concerns of a communication or swallowing problem or related functional issue. Treatment establishes a new skill or ability or remediates or restores an impaired skill or ability.

ODP Improvement Strategies

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- ISP revisions – to include risk assessment/mitigation
- Orientation Package for new providers
- Require residential providers to complete the dual diagnosis training
- Establish a Learning Collaborative for Residential Agencies
- Development of a Framework for a Successful Residential Program
- Adoption of the Health Risk Screening Tool (HRST) - a web-based screening instrument designed to detect health destabilization early and prevent preventable illness, health related events and even death http://hrstonline.com/

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Provider Strategies