Themes from HCBS Expert Call Discussions

This document is organized into three sections. The first section summarizes panelists' comments about the validity of the indictors as a set and concerns about their use. The second section lists factors that panelists believed might impact hospitalizations for the indicator conditions or events in the HCBS populations. These factors are organized according to the categories identified during conceptual model discussions. The third section summarizes panelists' comments and concerns about each indicator. Some of the material in this section is also included in section I or II, but is repeated to provide a single place to review all comments about a particular indicator.

I. Overall Validity

Clarification of HCBS Population and Program Services

In response to their review of the proposed indicator lists, a number of experts clarified the nature of HCBS programs, the populations they serve, and the services they provide. They noted:

- HCBS services are not medical services received at home. HCBS service providers are not typically nurses going into the home. State programs provide personal care services to support activities of daily living (ADLs), but these are provided by non-clinical attendants, not medical staff.
- These HCBS care providers are not clinically knowledgeable or oriented and therefore, program administrators are likely to question whether they are really responsible for the clinically-focused indicator outcomes.
- In the words of one concerned panelist upon reviewing the candidate indicator list, "This list reads like something written by someone that doesn't know what the HCBS population is. For example, 50% of the HCBS population is non-elderly."
- One panelist felt that the literature review has language in it that is outdated and may be of concern to the disability community. He recommended revising the literature reviews to include person-centered terminology that better fits within current norms in the disability community.
- One expert expressly noted that the indicators were not valid measures of quality for HCBS services.*
- The available literature is skewed towards the elderly population, who comprise only a portion of those receiving waivers.

*We did clarify that the intent of the indicators is to measure the health and well-being of HCBS beneficiaries, not to directly measure the quality of HCBS services.

Questions about accountability

Two panelists with policy expertise worried that Medicaid administrators would react negatively to the proposed indicators. Among their specific concerns:

- HCBS administrators feel they shouldn't be held accountable for clinical indicators
- Medicaid administrators will want to know who the audience is for the measures and get clarification on who is expected to act on the results.

Are Hospital Admissions an Appropriate Outcome?

A number of panelists were concerned that hospital admissions are not an appropriate outcome for measuring the health and well-being of HCBS beneficiaries. Chief among their concerns

was that HCBS focuses on providing support services, not medical care, and clinically-focused indicators miss the target.

Specific panelist comments included:

- Many of these indicator topics are not the main issues of concern in HCBS services currently, and shouldn't be the focus for assessing health and well-being. Things that should be of concern include: Is the person able to maintain their independence at home rather than long-term care? Do they stay alive? Do they go out and do things? They strongly suggested that focusing on hospitalizations would detract from these other factors, and could be deleterious to the overall well-being of the population.
- Taking a "medical model" approach is a good way to assure rejection from the disability community. This measurement approach is an extreme example of a medical model.
- Hospitalizations should comprise only a small part of a measurement strategy. Out of 20 ideal measures, 1 should focus on hospitalizations, and the other 19 on other aspects of HCBS. This expert stated that from the whole list of candidate measures, he would maybe keep 3 of the indicators. Of all the PQI-based indicators, he would only consider keeping dehydration.
- One expert suggested that for each indicator we (or others) need to think through the logic of how HCBS services might impact the indicator outcome. How closely related are the services and the outcome?
- One panelist recommended that if there is no other choice than these candidates, we should shorten the list, including maybe eliminating the accidents indicators. Her overall preference, however, would be not to rely on hospital admissions as an outcome.
- In defense of hospitalization as an outcome, one panelist stated that for populations receiving assistance at home, hospitalization or poor management might be a reflection of the home care, not the quality of outpatient care. Another panelist voiced support specifically for measuring rates of hospitalizations related to medical conditions, such as diabetes, in people with mental illness.

Perceived Disconnect Between Measure Scan and Proposed Indicators

Panelists familiar with the initial measure scan were surprised and disappointed to see that the candidate indicator set focused exclusively on hospital-based measures, rather than on measures of social support.

- They felt that these measures may be useful in the short-term, given that they rely on existing data sources, but may not be meaningful in the long run.
- To avoid alienating others familiar with the measure scan, they suggested that it might be helpful to have some documentation of why AHRQ settled on the hospital-based measures.

Are Hospital Admissions a Sufficiently Sensitive Outcome?

Many panelists were also concerned that hospitalizations are not sufficiently sensitive to detect poor care. They felt that hospitalization sets the threshold for "poor care" too high. Their comments focused on three key concerns:

- Using hospital admissions sets the bar too high. As an example, one panelist noted that because there is a large emphasis on providing hydration therapy in HCBS, dehydration occurs very rarely and therefore serves only to indicate terrible care, rather than distinguishing good care from poor care.
- Many concerning outcomes might occur that would be of interest for measurement but would not result in a hospital admission and thus would not be detected by these indicators. As an example, one panelist commented that only the most severe cases of

physical and sexual abuse or other trauma will result in hospitalization. The indicators miss dangerous events that are not sufficiently severe to require hospitalization.
- Some of the indicators, specifically those covering accidental injuries and abuse, will be very rare events and therefore the indicator rates may be difficult to interpret. Some panelists believed that rates of these events in HCBS populations were unlikely to differ from the general population. Of particular concern were firearms accidents and accidental drowning.

Suggestions for Alternative or Additional Outcomes

Panelists suggested a number of additional or alternative outcomes to consider examining, while also recognizing that these may not be feasible within the current project.

Alternative Endpoints:
- Emergency room use (for the same kinds of events).
- Codes on payment files [presumably outpatient?] might be useful as a level of data that captures events that are less severe than hospitalization.
- Critical events, as tracked by state agencies.
    - Panelists debated how useful this would be. Licensed sites are required to report critical events, but one panelist noted that over half of HCBS beneficiaries don't live in a licensed site.
    - Another panelist noted that most states have an Incident Management reporting system (sometimes referred to as "Unusual Incidents") that gathers information that could serve as additional or alternative outcomes, although states do not necessarily collect this information in a consistent manner.

Alternatives to the Current Clinical Focus:
- Examine adverse consequences of unmet needs.
- Consider measures such as the Participant Experiences Survey (developed for CMS) that focuses on adverse consequences, autonomy, satisfaction with service providers, etc.
- Large weight gain or weight loss might be useful because weight changes occur more frequently than hospitalization and can be indicative of changes in care quality in the HCBS population.
- Dental procedures.

Are The Indicator Conditions and Events Preventable?

Panelists held mixed opinions on whether care and services provided by HCBS can prevent hospitalization for the indicator conditions and events.

PQIs
- Although panelists did not agree that all PQIs were preventable, there was support for the idea that rates should be minimized when beneficiaries are receiving high quality care and support services.
- One panelist commented that some of her research has shown a link between self-report of unmet needs for help in the home with adverse consequences, including hospitalization for falls and PQI-type conditions. She cautioned that this research is still undergoing peer review, but believed that it provided some evidence to support the idea that poor in-home support may be associated with higher rates of PQIs.

- Other panelists still objected to the use of clinically-oriented indicators for measuring the health and well-being of HCBS recipients. (See the section titled, "Is Hospitalization an Appropriate Outcome?")
- Several panelists suggested eliminating the perforated appendix indicator. They noted that rates of perforated appendix were unlikely to differ from the general population and that perforation was unlikely to be preventable. The condition may be less preventable in some populations who cannot communicate symptoms or who have atypical presentations.
- A number of panelists noted that some medications, in particular psychotropic drugs and protease inhibitors, can increase the risk of diabetes, including type II diabetes. This puts people with mental illness, intellectual or developmental disabilities, and HIV at higher risk for diabetes.

Accidental Injuries and Abuse

- Several panelists questioned the utility of the fire and burns indicator. They felt that fires may not be preventable. They also noted that the rate of hospitalization for fires may not be a true reflection of the number of serious fire-related injuries as some people may die before reaching the hospital.
- A number of panelists also questioned the utility of the firearms accident indicator. They commented that these events are likely to be extremely rare, particularly given that licensing regulations prohibit firearms at residential facilities serving HCBS populations or require them to be locked at all times. Another panelist noted that when firearms accidents do occur they probably do not happen while the HCBS service provider is present and therefore may be beyond the control of HCBS programs. Certain populations may be at higher risk of violence, such as substance abusers.
- There was broad support for the injurious falls indicator. Although particularly important to examine in the elderly, panelists noted that falls are also a problem in other HCBS populations, such as those with motor disabilities, dementia, intellectual or developmental disabilities and patients with brain injuries who may have trouble remembering to use mobility devices or who lack impulse control. One panelist noted that not all falls will result in a hospitalization, limiting the sensitivity of this indicator. Another panelist cautioned that falls may be common but not preventable in populations at risk for seizures, such as those with intellectual or developmental disabilities.

Mental Illness and Substance Abuse

Panelists' opinions about the ability of HCBS programs to prevent hospitalizations for mental illness and substance abuse varied widely. Their comments included:

- It is unclear how support services are supposed to prevent these kinds of admissions.
- With care coordination and care management, treatment under HCBS could have a positive impact on someone's ability to stay out of the hospital.
- It is hard enough to train staff just to support ADLs. HCBS services are not intended to provide psychological assessments with a mind to preventing psychiatric admissions.
- Psychiatric hospitalization rates may depend on practice patterns and local availability of psychiatric beds. The indicator may be less valid if in-patient psychiatric services are in short supply.
- Many states are facing up to 30% in Mental Health budget cutbacks and caseloads are increasing. Most current caseloads may be far larger than those on which evidence for effectiveness of interventions was based. For example an ideal caseload may be 10

patients per case manager; however, many states typically have 30-70 patients per case manager.
- Psychiatric facilities may not feel comfortable caring for patients with severe comorbidities, who may then be admitted to an acute care hospital with a medical diagnosis, rather than a psychiatric admission.

Pressure Ulcer
- A number of experts agreed that the pressure ulcer indicator was more tightly linked to HCBS-controlled services. They felt that HCBS support staff clearly should be helping to mitigate pressure ulcers.
- Another panelists noted that if a patient was admitted where the primary reason was pressure ulcer, she would want to know about that.

Potential Adverse Consequences of the Indicators

Panelists brought up a limited number of concerns about potential adverse consequences of the proposed indicator set. These included:
- These indicators represent just a small part of the health and well-being for HCBS populations. One panelist worried that users would over-focus on these hospital-based indicators, and thus hospitalizations, neglecting other important aspects of quality for these populations.
- Another panelist was concerned that even if indicator rates are released with caveats, they will inevitably be used to rate and compare programs. She felt this would be problematic given her expectation that Medicaid administrators will react negatively to the indicators as currently proposed. She felt consideration was needed about how the indicators can be altered to allay some of the concerns from those in the field. She herself did not have suggestions for how to do that.
- Another panelist worried specifically that the medication error indicator could provide a disincentive for reporting those kinds of events.

Measurement Considerations

Reliability
- A number of panelists expressed concern that certain indicator events would be very rare, making indicator rates difficult to interpret. Panelists specifically raised concerns about the accidents and abuse indicators (especially firearms accidents) and perforated appendix.
- One panelist felt that a single mental illness measure would not be sufficiently reliable.

Potential Bias

Panelists discussed a number of factors that might lead to bias in rates for particular indicators in particular populations. These factors are reviewed in-depth in the section to follow (Conceptual Model: Factors Potentially Impacting Indicator Rates), but a few such concerns that apply broadly included:

- Some accidents won't result in a hospitalization because the person dies before reaching the hospital. Panelists worried about this potential bias in particular for fires/burns and accidental drowning. They suggested that using emergency department data may capture some additional cases, but would still miss persons pronounced dead on site.
- During one call, a panelist brought up a concern that in some cases higher levels of support might uncover events or problems that lead to a hospitalization captured by one of

the indicators, whereas similar beneficiaries receiving less support may not be admitted for an indicator diagnosis (either due to death or admission under another diagnosis). Others on the call felt that further exploration was needed, including considering who might catch such problems, how does their awareness of the problem lead to an indicator-captured hospitalization, and if no support person was present, would the patient never end up in the hospital for the QI event, or would it just be delayed?

- One panelist commented that issues of inappropriate oversight might affect rates for the PQI-based indicators, but that they are more strongly affected by the underlying disease of the patients. Even with perfect care some patients will have episodic admissions, so the underlying indicator rate is determined more by disease severity.
- Thus, small differences between comparison groups in the PQI-based set of indicators would be unimportant. But in the set of injury and abuse indicators, even small differences would be important to investigate because they should be rare events.

Threshold for Admission and Coding Practices

Admitting practices vary for certain HCBS populations, such as:

- Patients with AIDS are more severe clinically and in some cases will have a lower threshold for admission. But current coding makes it difficult to distinguish these more severe AIDS patients from those with HIV who are functioning well.
- Patients with clinically significant HIV or AIDS may be more likely to be admitted for bacterial infections, but probably not for other injuries or PQI conditions included in the indicator set.

Coding practices may impact admission rates for certain groups or diagnoses:

- Due to reimbursement policy, HIV is often coded as the primary diagnosis regardless of the true reason for admission. Often thrush is coded as the secondary diagnosis and the real reason for admission is in the third position.
- In the elderly, dementia might be the underlying reason for admission, but dementia is less likely to be coded than other comorbidities, like CHF.
- In the MR/DD/ID population, pneumonia is almost always listed as aspiration pneumonia regardless of the actual cause of pneumonia. In many cases the actual cause is unknown.
- The diagnosis of intellectual or developmental disability is not always included in admission records.
- In people with motor disabilities or the inability to swallow or move their chest wall, asthma may be coded as COPD or restricted airway disease.
- Medical diagnoses may be listed before mental health diagnoses, even if the mental health considerations precipitated the hospitalization

II. Conceptual Model: Factors Potentially Impacting Indicator Rates

Panelists identified a wide range of factors that may impact hospitalization rates for particular indicators in particular populations. In this section, we grouped these comments according to the set of potentially important factors identified in the conceptual model.

Clinical Characteristics/Health Status

- Patients taking antipsychotic medications or protease inhibitors are at increased risk for weight gain and diabetes. This especially impacts the MR/DD/ID population and those with mental illness (antipsychotic medications) and the HIV population (protease inhibitors).
- People with motor disabilities or who lack the ability to swallow or move their chest wall are at higher risk for asthma and respiratory disorders.
- People with developmental disabilities (such as spina bifida), spinal cord injury, catheterizations, and urinary abnormalities are at higher risk for UTI.
- HIV patients may be more likely to get salmonella and gastroenteritis, although their risk depends on the state of disease. The more advanced their HIV, the higher the risk for more advanced gastroenteritis.
- Cognitive issues and impulse control can contribute to falls if patients forget or refuse to use their walker, especially at home.
- Pain is also a problem for falls, both because patients in pain may be more likely to fall due to impeded gait and because they may be more likely to be admitted after a fall.
- A large number of people in the MR/DD/ID population have an increased risk of injury with falls, possibly due to bone density changes.
- The population with severe mental illness generally has serious comorbidities, including diabetes and cardiovascular disease, which often exacerbate the mental health issues. Some data suggest that patients with serious mental illness die approximately 25 years sooner than the general population.
- Serious mental illness is more prevalent in the HIV population. This includes schizophrenia, bipolar, or Major Depressive Disorder.
- One panelist felt that for many elderly patients with chronic conditions, it is only a matter of time until they end up in the hospital.
- Another panelist felt that although issues of inappropriate oversight might affect rates for the PQI-based indicators, they are likely more strongly affected by the underlying disease severity of the patients. Even with perfect care some patients will have episodic admissions.

Predisposing Factors

- The risk of falls increases as patients age and develop gait problems.
- Several panelists noted that socioeconomic status and race affect admission rates to both hospitals and jails. (This was brought up in the context of the population with mental illness).

Risk Factors/Lifestyle/Behaviors

- People with mental health issues smoke at a much higher rate than the general population. (One panelist estimated that 70-80% of schizophrenics smoke). This greatly impacts physical health and medical care.
- Violence may be more prevalent in the HIV population. This is not because of HIV status, but rather most likely a correlate of other characteristics of the HIV population, such as substance abuse.

- People with TBI often have problems with social skills, which can increase their chances of being abused or assaulted because they put themselves in riskier situations and can't read warning signs very well.
- Past history of trauma may affect how patients participate in outpatient care. This may be what triggers the hospitalization, not necessarily the mental illness. One panelist commented that the impact of trauma may be substantial for persons with mental illness, noting that homeless women with serious mental illness have a 98% rate of being previously traumatized. People with a history of trauma may be hospitalized more frequently for mental illness than those without previous trauma. However, it is unlikely that we can reliably identify patients with a history of trauma using only administrative data.
- The homeless are more likely to be physically assaulted and have an associated hospitalization. Mental illness is also a factor in getting into high-risk situations.
- One expert in mental health felt that these hospitalizations are preventable with illness recovery services and good case management, which can help individuals identify and avoid risky situations.
- Admissions due to cold exposure will be more common in the homeless population.
- Patients with HIV are more likely to also have mental illness and substance abuse (a "comorbid trifecta").
- Although there was not much discussion of risk adjustment, one panelist suggested that lifestyle factors such as obesity or smoking should not be included in risk adjustment models because HCBS programs should be handling these issues as well, even if they are not the primary focus of care. Another panelist disagreed and felt that these factors should be included in risk adjustment. Both panelists agreed that if only HCBS beneficiaries are included in analyses (i.e., institutionalized patients excluded), then it's much more complicated to sort out what to control for in risk adjustment models.

Environmental Factors

- Diabetes and cardiovascular disease are problems for people without access to exercise facilities and healthy foods. This is especially a problem in inner cities and is primarily related to socioeconomic status (SES).
- Suicide rates are generally related to the level of the economy, availability of health insurance, and strictness of gun control.
- Firearms are prohibited at licensed facilities in many states, which will likely impact the rate of firearms accidents among the population living in such facilities.

Social Factors

- The TBI population typically requires an intense level of care but lacks support in the community beyond family. When that informal support system tires or breaks, then the patient is often hospitalized as a means of respite care. These admissions might be coded as "late effects of brain injury" but also could be coded as a variety of other medical diagnoses which would be difficult to identify and track.
- However, one expert in the TBI population felt that providing sufficient support to avoid "respite care" admissions should be within HCBS control and therefore should be preventable.
- Among the HIV population, the threshold for admission may be lower in patients who have less support, who are less reliable in accessing the care system, or who are less able to register or interpret worsening symptoms. But the threshold for social admission among HIV patients is not necessarily different from social admissions in the general population.

Healthcare Delivery System Factors

Locus of Care

- It can be difficult to admit patients with TBI or SCI into psychiatric hospitals or psychiatric wards of acute care hospitals even when the reason for admission is mental illness. These patients may instead be admitted to a medical floor of an acute care hospital. The same problem sometimes arises for HIV patients.
- Institutional settings, as opposed to HCBS, often provide services that people in the community would typically turn to the hospitals for. Thus, people in institutions are essentially already in a hospital-like setting, yet there are no actual admissions to be documented since there is no transfer to an actual hospital. It might be informative to look at the specific treatments people are getting, regardless of their care location, rather than focus simply on the admissions data (e.g., look at outpatient encounters). The Medicaid payment files may be useful for this.

Caretaker Management

- Support services can assist with medication management for patients with serious mental illness, who may have trouble managing medications alone due to issues of disorganization.
- Failures in medication management may result in exacerbations of mental illness, for example if a patient goes without medication for several days due to a lapse in support services.
- Patient education can also help prevent medication complications. For example, some medications carry increased risks during hot weather. Education in the spring time about the dangers of dehydration and heat stroke may help prevent some admissions during the summer.

Clinical Management

- TBI patients may be admitted for medication adjustment if they have residual agitation and irritability. Treatment of certain conditions, such as spasticity, are only available as an inpatient.
- TBI patients are at higher risk for delirium and are more likely to be admitted if they present with delirium because it's difficult to manage a delirious patient and it's often unclear what is causing the delirium. This may complicate interpretation of the dehydration indicator.
- Comorbid illness, particularly mental illness, can complicate medication management in patients with TBI. For example, because of the brain injury, patients may not be able to recognize problems during medication adjustment. But panelists expected that it would be very rare to admit a TBI patient for problems of medication administration.
- TBI patients who fall may be admitted in order to receive therapy to correct the gait problem at the root of the fall, not necessarily because the fall injury was so severe that it required a hospitalization. However, such admissions would normally be to a rehabilitation facility rather than to an acute care hospital.
- In the MR/DD/ID population, anti-psychotic medications are often prescribed for reducing a problematic behavior even in the absence of a true mental illness.
- In the HIV population, dehydration is a frequent problem and may be due to a variety of causes, such as failure to thrive, excessive gastroenteritis, or not taking medications. Not all clinics can provide IV fluids as an outpatient.
- The HIV population is at increased risk for complications from medication interactions because these patients take so many different medications. HIV drugs interact with themselves, but also with lipid-lowering agents and anti-retroviral medications. Physicians who specialize in HIV are aware of these potential interactions, but other physicians may not be. Pharmacy programs to flag potential drug-drug interactions may help prevent these complications.

- However, it is difficult to determine which of these medication interactions are preventable. In some cases physicians continue giving patients drug combinations with potentially problematic interactions either because the patient has not yet experienced a complication, or because they determine that the risk of harm is greater if the patient does not receive the medications. In some cases these complications will be coded as an adverse drug event as a result of properly administered drugs, but HIV patients may also be more likely to be admitted for incorrectly administered drugs.

Self-care

- Management of chronic disease is complicated in patients with cognitive impairment. For example, patients with TBI who suffer from memory impairment may have difficulty remembering what they ate or when they last took insulin, which makes it difficult for them to comply with diabetes management.
- Impaired impulse control is also a problem in disease management for those with brain injuries.
- In those with serious mental illness, issues of disorganization may interfere with medication management.

Access to Healthcare System

- Some medication errors may be due to patients' inability to afford medications.
- Without a significant support network in place, patients with TBI often do not use outpatient services so they end up in the ER.
- Once a patient is in the ER, the threshold for admission is often lower.
- Patients that "fall through the cracks" of services often end up homeless.
- Some data suggest that patients with serious mental illness die approximately 25 years sooner than the general population. These deaths often occur because of a physical ailment that may be attributable to poor access to primary care and poverty.
- Patients with TBI often have dual diagnoses (e.g., TBI and mental illness or substance abuse) that make it difficult for them to access services. Rehabilitation facilities specializing in treating TBI don't feel comfortable managing the mental illness or substance abuse, and psychiatric facilities don't feel comfortable managing the brain injury. Patients with spinal cord injury and mental health disorders may fall into the same grey zone.

Practice Patterns

- Local practice and cultural patterns influence where patients receive care. One panelist noted that in Mississippi some patients were cared for at home even when in a vegetative state and so had to be periodically hospitalized for management. But in other areas such patients would almost always be cared for in an institutional setting.
- Use of restraint in the emergency department varies according to practice characteristics and local culture, but ambulances transporting patients for psychiatric holds are required to use 5-point restraint regardless of the patient's condition. Agitation tends to increase with use of restraint, which may be associated with involuntary commitment for the mentally ill. Some admissions for mental illness may be preventable if restraint use is minimized.

Availability of Services

- Hospital admission is not a uniform indicator of severity. It depends on access to urgent care, the type of community the patient resides in, and the level of health care the patient has access to, among other factors. For example, urban hospitals probably see more severe patients than do rural hospitals, because patients in urban areas have access to alternative health care services, such as urgent care clinics, where they can receive care for less severe problems.

- Support services available in the community are not always a good fit for the TBI population. For example, a young person with TBI is a poor fit in an adult daycare program that is geared towards the elderly. Adult daycare centers don't have the training to deal with behavioral problems that are particular to the TBI population.
- The number of beds available for psychiatric admissions compared to the population will vary across states. This may cause diversion to other institutional settings for patients with psychiatric presentations. For example, lower rates of psychiatric admissions are generally accompanied by higher rates of jail admissions. However, one panelist cautioned that it is difficult to pick apart a jail admission for a psychiatric disorder versus for crime.

Insurance/Enabling Factors

- Suicide rates are generally related to the level of the economy, availability of health insurance, and strictness of gun control.

HCBS factors

- The populations who have access to HCBS services vary by state depending on which services each state provides and their policies about who qualifies for which types of care. This can impact admissions data and may confound interpretation of indicator rates when comparing states. Cataloguing individuals' characteristics (and differentiating patients by severity) might be helpful in evaluating the care provided by different states.
- For example, some states provide HCBS services to all people with developmental disabilities, while other states use other programs for people with severe health conditions. The latter set of states will likely report fewer hospitalizations among their HCBS beneficiaries because their HCBS populations are not as sick.
- One way to mitigate this confounding would be to examine factors that are predictive of health events, such as severity of health concerns.
- One panelist argued against controlling for state policies during initial measure evaluation. She felt that this question should instead be addressed after all data was collected.
- One panelist noted that due to low Medicaid reimbursement rates for inpatient psychiatric care, the availability of these services has declined in his state.
- One panelist commented that cross-state comparisons in indicator rates could be useful in raising awareness about the need for consistent HCBS provider training across states.

Insurance Coverage/Enabling Factors

- The basis of support for the elderly varies from state to state, particularly in the balance between Medicaid-provided services and those covered under the Elderly Americans Act and Title III funds. This means there is shared accountability for the medical condition-based indicators (PQIs).

III. Indicator-Specific Comments

Some of the material in this section is also included in section I or II, but is repeated here to provide a single place to review all comments about a particular indicator.

I. PQI-based Indicators

A. Chronic conditions

1. Diabetes (both short-term complications and uncontrolled diabetes)
   - Many panelists noted that certain medications, in particular anti-psychotic drugs and protease inhibitors, carry an increased risk for diabetes. This will especially impact people with HIV, mental illness or intellectual or developmental disabilities (who are often prescribed anti-psychotic medications for controlling behavior rather than true comorbid mental illness).
   - One panelist believed that diabetes is associated with poor care in the home.
   - Providing a dietician to consult for a diabetic would fall under HCBS program responsibility.
   - Diabetes is a problem for people without access to exercise facilities and healthy foods. This is especially a problem in inner cities and is primarily related to socioeconomic status (SES).
   - Management of chronic disease is complicated in patients with cognitive impairment. For example, patients with TBI who suffer from memory impairment may have difficulty remembering what they ate or when they last took insulin, which makes it difficult for them to comply with diabetes management. HCBS programs may or may not be able to address these issues.

2. Asthma
   - People with motor disabilities and who lack the ability to swallow or move their chest wall are at increased risk for asthma and other respiratory disorders.
   - Asthma may get labeled as COPD or restricted airway disease more often in these populations.
   - An expert in the HIV population did not expect any higher prevalence of asthma in the HIV population as compared to HIV negative patients with similar risk factors.

3. Congestive Heart Failure
   - One panelist believed that CHF is associated with poor care in the home.
   - An expert in the HIV population did not expect any higher prevalence of CHF in the HIV population as compared to HIV negative patients with similar risk factors.
   - People with mental health issues smoke at a much higher rate than the general population. (One panelist estimated that 70-80% of schizophrenics smoke).
   - Cardiovascular disease is a problem for people without access to exercise facilities and healthy foods. This is especially a problem in inner cities and is primarily related to socioeconomic status (SES). Panelists felt that weight management should be an ongoing focus for HCBS service providers.
   - Impaired impulse control impacts disease management for those with brain injuries.

B. Acute conditions

1. Bacterial pneumonia
   - Panelists recommended including aspiration pneumonia in the numerator definition of bacterial pneumonia, at least for the MR/DD/ID population, because admissions for pneumonia in these patients are almost always labeled as aspiration pneumonia,

regardless of the actual cause or whether it is known. (Cultures are rarely performed). This may be partially driven by higher reimbursement rates for aspiration pneumonia.
- Dysphagia, if properly managed, should be avoidable so aspiration pneumonia should be preventable.

2. UTI
- Several panelists agreed that admissions for UTI may indicate problems with insufficient hydration and poor hygiene, which should be addressed by HCBS.
- Some patient groups are at high risk for UTI, including those with developmental neurological impairment, such as spina bifida, and spinal cord injury, urinary abnormalities and patients with catheters.
- Certain HCBS populations may have a higher percentage of patients with communication impairment or with atypical UTI presentation, increasing the risk of UTI with complications.

3. Infection Due to Prosthesis Use
- One panelist questioned whether hospitalizations for such infections are really preventable. Joint infections could be of the result of injection drug use, but they could also be due to poor hand washing, or nosocomial infection.
- One panelist suggested examining wound infections rather than infection due to prosthesis use. A broader category may be better than focusing specifically on prosthesis use alone.
- Patients with clinically significant HIV or AIDS may be more likely to be admitted for bacterial infections.

4. Dehydration and Hypernatremia
- Dehydration was a particular concern for many of the HCBS populations, including the elderly, the MR/DD/ID population, and the HIV population.
- HIV patients may be more likely to get salmonella and gastroenteritis, which increases their risk for dehydration. Dehydration may also result from failure to take medications or failure to thrive. But there is probably not an increased risk for hypernatremia in this population.
- One panelist noted that providing adequate hydration and meals might fall under an HCBS program if those activities are covered as part of the beneficiary's care plan.
- Other panelists believed that hospitalization for dehydration was an indicator of inadequate support services.
- One panelist noted that there is a large emphasis on providing hydration therapy in HCBS. As a result, he expected that it occurs very rarely and therefore may not make a good indicator.
- In the TBI population, it may be difficult to interpret the dehydration indicator because TBI patients are at higher risk for delirium and are more likely to be admitted if they present with delirium.

5. Perforated appendix
- Several panelists advocated for eliminating the perforated appendix indicator. Rationales for exclusion included that perforated appendix is a rare event and that it probably is not preventable.
- A number of experts questioned whether the rate of perforated appendix differs in HCBS populations (such as MR/DD/ID and HIV) from the general population. This can be examined empirically during a later stage of measure development.

- In the MR/DD/ID population, problems reading a patient's communication of symptoms or pain may lead to delays in care. Whether or not such delays are preventable is a separate question.

II. Accidents and Injuries

A. Assault and Abuse

- Only the most severe cases of abuse or assault will result in hospitalization and thus we may not capture a lot of data on extremely dangerous events that just aren't "bad enough" to require hospitalization. The threshold may be set too high with hospitalization being the only setting evaluated.
- Violence may be more prevalent in the HIV population. This is not because of HIV status, but rather most likely a correlate of other characteristics of the HIV population, such as substance abuse.
- People with TBI often have problems with social skills, which can increase their chances of being abused or assaulted because they put themselves in riskier situations and can't read warning signs very well.
- The homeless are more likely to be physically assaulted and have an associated hospitalization. Mental illness is also a factor in getting into high-risk situations.

B. Unintentional Injuries Potentially Due to Neglect

- One panelist advocated for eliminating all the accidental injury indicators because they seemed less directly related to in-home care than other indicators (such as the PQIs).
- Another panelist commented that we want a system that responds to injuries even if they don't result in a hospitalization.

1. Fire/burns/smoke inhalation
   - A number of panelists noted that people who die on-site in fires will not have a hospitalization and therefore will be missed by this indicator.
   - One expert questioned whether injuries due to fires are preventable.

2. Accidental poisoning
   - In the MR/DD/ID population, accidental poisoning with household products such as cleaning solutions are not uncommon. Such events reflect of quality of home care (not outpatient care or access to health care).

3. Firearms accidents
   - A number of panelists expected firearms accidents to be extremely rare, limiting the usefulness of this indicator.
   - Licensing regulations for residential settings generally prohibit firearms or require them to be locked at all times, which should limit the prevalence of firearms accidents. However, one panelist noted that more than half of HCBS recipients do not reside in a licensed facility. Other firearm regulations vary by state and may impact the likelihood of accidents,
   - One panelist commented that firearms accidents are unlikely to occur when HCBS support staff are present, suggesting that they do not fall under HCBS control.

4. Drowning
   - Rates of drowning may be higher in the individuals who are unable to move who might drown if left unattended.

- Accidental drowning has occurred in people with seizure disorders who were capable of bathing independently, but had a seizure while bathing and drowned.

5. Heat/cold exposure
   - The homeless population is at greater risk for health events related to cold exposure.
   - Certain psychiatric medications carry increased risks for complications, such as dehydration and heat stroke, during hot weather. Although, education efforts may help raise awareness about these risks and reduce associated hospitalizations.

6. Injurious falls
- There was broad support for the injurious falls indicator. Many HCBS populations are at risk for falls, including the elderly, those with motor disabilities, dementia, intellectual or developmental disabilities and patients with brain injuries.
- Many in the MR/DD/ID population are at increased risk for injury from falls due to bone density changes.
- The risk of falls increases as patients age and develop gait problems.
- Methods to prevent falls in these populations are similar to those developed for the elderly.
- Falls may be common but not preventable in populations at risk for seizures, such as those with intellectual or developmental disabilities.
- Falls related to seizures are more common in the MR/DD/ID population, but might not be preventable. Seizures are much more common in the ID population (21% in those without cerebral palsy and 50% in those with cerebral palsy) than the general population (0.6 to 1.0%) and complex seizures are even more common.
- One panelist noted that not all falls will result in a hospitalization, limiting the sensitivity of this indicator. They felt that these injuries were still important to capture.
- Cognitive issues and impulse control also can contribute to falls if patients forget or refuse to use their walker, especially at home.
- Pain is also a problem, both because patients in pain may be more likely to fall (due to impeded gait) and because they may be more likely to be admitted after a fall. Most of these patients can be managed in an outpatient setting after the fall, but it does increase the chances of hospitalization.
- People with neurologic conditions are more likely to fall. This includes the HIV population with neurologic complications, particularly as the disease advances. But HIV itself does not present an added fall risk.

III. Mental Illness and Self-Inflicted Injuries

A. Serious Mental Illness and Self-Inflicted Harm

- One panelist was concerned that these indicators are not sufficiently specific because hospitalization for mental illness is so common.
- One panelist felt that further clarification of this indicator is needed: Does it apply to the whole HCBS population, or does it only apply to those individuals with established mental illness diagnoses, who can be difficult to identify?
- Another panelist felt that a single mental illness measure would not be sufficiently reliable.
- In the elderly population, most psychiatric admissions are not for typical mental illness diagnoses such as bipolar disorder or schizophrenia, but rather are for behavioral problems associated with dementia.

- Psychiatric admissions for behavior problems, rather than mental illness, are likely also a problem in the MR/DD/ID population. Although there may be concomitant mental illness, it may be behavior, rather than a mental health exacerbation, that triggers the hospitalization.
- Panelists agreed that it can be difficult to get appropriate mental health care for patients with both a disability and mental illness. For example, in one panelist's experience, it is extremely difficult to get psychiatric hospitals to admit patients with traumatic brain injury or sometimes spinal cord injury. These patients may be admitted to a medical floor of an acute care hospital with a mental illness diagnosis, rather than being admitted to a psychiatric hospital or even the psychiatric ward of an acute care hospital. Similarly, patients with HIV may be admitted to a medical floor for mental health disorders because psychiatric wards/hospitals do not feel comfortable caring for patients with HIV.
- Other panelists noted that patients may be admitted with a medical diagnosis even when the underlying trigger for admission is a mental health concern.
- One panelist questioned the validity of these indicators in areas where inpatient psychiatric care is unavailable or in very short supply.
- Serious mental illness is more prevalent in HIV population. This includes schizophrenia, bipolar disorder, or Major Depressive Disorder.
- People with intellectual disabilities are sometimes hospitalized for self-injurious behavior that is ultimately due to an underlying but undetected physical problem. The self-harm often stops once the underlying problem is resolved. This is especially a problem in patients who have trouble communicating.
- Suicide rates are generally related to the level of the economy, availability of health insurance, and strictness of gun control.
- In addition to including diagnosis codes for self-harm, one panelist suggested also examining codes for patients posing a threat of harm to others. He noted that a person with depression may be hospitalized for suicidal behavior, while someone with schizophrenia may be hospitalized for being a threat to others.

B. Substance Abuse

- In general substance abuse is probably less of a problem with most waiver recipients for intellectual disabilities since they have to meet the ICF/MR functional criteria and many of them either live in residential settings or with their families.

C. Dual Diagnosis of Mental Illness and Substance Abuse

- Patients with HIV are more likely to also have mental illness and substance abuse issues.

IV. Medication Errors

- Several experts asked who is really accountable for this indicator. They questioned whether HCBS caregivers are the ones administering medications and whether responsibility for administering medications fell within the purview of HCBS.
- Another expert felt that this indicator puts pressure on the states to be accountable for a lot of people in the chain of custody for each medication.
- However, other panelists noted that support services can help prevent medication errors. Examples of such services included pharmacy programs to pre-package medications in daily doses and efforts to educate patients about potential complications. For example, some medications carry increased risks during hot weather. Education in the spring time about the dangers of dehydration and heat stroke may help prevent some admissions during the summer.

- Some medication errors may be due to patients' inability to afford medications.
- One panelist worried that counting only errors resulting in a hospitalization set the threshold for quality too low. She felt that also including errors that do not result in a hospitalization would make the indicator more useful.
- Another panelist suggested that this indicator should be labeled "medication problems" because common problems, such as overdoses and drug-drug interactions, are not generally errors we are attempting to capture through the indicators.
- The HIV population may be at higher risk for errors in medication administration because they take so many medications.
- In the MR/DD/ID population, errors of omissions are more common with direct care staff and administration to the wrong person is proportionately more common with nurses. In Pennsylvania, the top three medication errors are omission (66%), wrong dose (17%) and wrong time (8%).
- Failures in medication management may result in exacerbations of mental illness, for example if a patient goes without medication for several days due to a lapse in support services. A resulting hospitalization may not be recognized as resulting from a medication error.
- Medication errors often are not recognized or categorized appropriately and there is variable reporting of such errors depending on the provider (and often on whether they address medication errors through punitive measures versus root cause analysis learning).
- One panelist worried that the medication error indicator could provide a disincentive for reporting those kinds of events.

V. Pressure Ulcers

- A number of experts agreed that the pressure ulcer indicator was more tightly linked to HCBS-controlled services. They felt that HCBS support staff clearly should be helping to mitigate pressure ulcers.
- An expert in the HIV population did not feel that there was increased risk for infection of pressure ulcer for these patients.
- No panelists felt comfortable addressing the question of which stages of pressure ulcer to include in the indicator definition. One noted that there were likely very few admissions where the primary diagnosis is a stage 1 or 2 pressure ulcer because he felt it would be difficult to justify admitting a patient for that. He suggested examining the data empirically to assess rates of admission by stage.
- Without present on admission (POA) data, it is difficult to know whether pressure ulcers coded as secondary diagnosis were hospital-acquired.
- One panelist worried about inconsistency in classification of pressure ulcers. She suggested modifying the indicator definition to include both a yes/no question (did they have a pressure ulcer?) and a specification of stage.

Suggestions for Additional or Different Indicators

- Panelists on the MR/DD/ID call suggested including indicators of chronic constipation and bowel obstruction, which are a frequent problem in this population related to medication and diet.
- One MR/DD/ID panelist also suggested including dental care indicators because many psychotropic medication cause growth of the gums, although this does not always lead to hospitalization. Some states have a dental clinic for people with developmental disabilities,

but most dentists don't have this expertise. Admission to the hospital for routine dental care may represent lack of professional expertise in the area.

- Another MR/DD/ID panelist suggested admission for seizure as another possible indicator for this population. Admission for "status epilepticus" may indicate a disorder that is not adequately controlled by medications.
- Another panelist suggested examining wound infections rather than infection due to prosthesis use. A broader category may be better than focusing specifically on prosthesis use alone.
- One panelist felt that malnutrition and obesity are common problems and should definitely be on the list of candidate indicators.
- One panelist felt that with prophylaxis, HIV patients are probably less likely to be hospitalized with opportunistic illnesses. She suggested admissions for opportunistic illnesses as a quality indicator for the HIV population.