

# **Home and Community-Based Services Quality Indicators:**

## **A Review of Literature Related to HCBS Populations**

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## Introduction and Methods

### Purpose

The purpose of this review is to provide context for development of the Home and Community Based Services (HCBS) Quality Indicator set. This context will be used primarily to guide interpretation of empirical analyses. This review is not intended to provide a comprehensive survey of the evidence of the proposed indicator events within all potential HCBS populations, but rather to provide an overview of the information most important to the development and interpretation of the candidate indicators in key groups of HCBS beneficiaries.

### Overview of Methods

We searched the published literature to identify key sources of information relevant to the proposed set of HCBS Quality Indicators (QI). We searched a number of online databases, including PubMed, PsychInfo, and ISI Web of Science. We stratified our search to address two specific lines of evidence. First, we searched PubMed and PsychInfo for articles that directly addressed the validity of using hospital admission for the proposed conditions as proxies for HCBS population wellbeing. This included those research questions identified with (\*) below. Second, we sought to identify additional information about these conditions in the HCBS populations that could provide insight into applying these indicators to these populations. For these questions, we narrowed our search to include only review articles. For all searches we included only English language articles published within the last 10 years. We also excluded articles that focused exclusively on children. In addition to searches of online databases, we sought input from experts on additional relevant sources, in particular government reports or other material not typically published in peer-reviewed journals.

We sought information on health conditions and events included in the set of candidate HCBS QIs. This included ambulatory care sensitive conditions covered by the AHRQ Prevention Quality Indicators (PQIs)<sup>1</sup> (diabetes, congestive heart failure, chronic obstructive pulmonary disorder, asthma, bacterial pneumonia, dehydration, urinary tract infection and perforated appendix); intentional injuries inflicted by others (abuse, neglect, physical violence); medication errors; pressure ulcers; accidental injuries potentially due to neglect (burns, poisoning, fire arms accidents, drowning, excessive heat or cold exposure, and falls); and mental illness and behavioral health events (serious and persistent mental illness, substance abuse, suicide and self harm). In addition, based upon expert feedback, we reviewed key literature pertaining to unmet needs of disabled populations. Appendix A includes a list of key words used to identify literature pertinent to key HCBS populations and QI health events and conditions.

### Research Questions

In seeking pertinent information, we were guided by a set of research questions:

- What is the prevalence of the health event or condition in key HCBS populations?
- What are important clinical considerations for this health event/condition in key HCBS populations?
- Is there evidence of poor clinical or self-care related to the health event/condition in key HCBS populations?

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<sup>1</sup> A review of published literature pertinent to the application of the AHRQ PQIs in the general population was recently updated and is available upon request. For more information, contact Sheryl Davies at [smdavies@stanford.edu](mailto:smdavies@stanford.edu).

- What is the frequency of exacerbation of the health event/condition in key HCBS populations and how is this linked to clinical and self-care? (Not applicable to all indicators)
- What is the evidence for prevention of the health event or hospitalization\* related to the health event/condition? (Not applicable to all indicators)
- What factors impact hospitalization for the health event/condition in key HCBS populations?\*
- What is known about documentation of and coding related to the health event/condition, including sensitivity and specificity?\*

### **Organization**

This review is organized into sections focusing on each of the broad categories of candidate QIs: PQIs, intentional injuries inflicted by others, medication errors, pressure ulcers, accidental injuries potentially due to neglect, serious and persistent mental illness and behavioral health events, and unmet needs. Within each section, we organized materials according to the guiding research questions. When feasible, we listed information separately for key HCBS populations. References cited are listed at the end of each section.

### **Included Populations**

States implement HCBS programs differently, leading to much heterogeneity in the composition of each state's HCBS population. We sought information specific to populations frequently included in HCBS programs, including people with intellectual and developmental disabilities (ID/DD), people with physical disabilities, people with mental illness, and elderly individuals. When we believed it to be pertinent, we also included limited information on candidate QI health events in the general population.

## Prevention Quality Indicators

For the purposes of this review, we sought information on ambulatory care sensitive conditions covered by a sub-set of the AHRQ Prevention Quality Indicators (PQI) to be considered for inclusion in the HCBS QI set: Diabetes, congestive heart failure (CHF), chronic obstructive pulmonary disorder (COPD), asthma, bacterial pneumonia, dehydration, urinary tract infection (UTI) and perforated appendix.

### ***HCBS populations included in this review***

- Evidence pertinent to elderly individuals, people eligible for both Medicaid and Medicare (dual eligibles), and socioeconomically disadvantaged persons was included in a separate general population PQI literature review.<sup>2</sup> Therefore, evidence related to these populations is not included here.
- We found no evidence highlighting special considerations for PQI condition related admissions among people with developmental or physical disabilities.
- Multiple studies highlighted age and comorbidities as risk factors for hospital admission. Frail, elderly individuals are considered in a separate general population PQI literature review<sup>2</sup> and are not included here.
- Multiple studies have found higher admission rates in areas with low socioeconomic status (SES) populations, and independent effects of SES on hospital admission for PQI conditions, although this effect appears to be less robust among those over age 65. It is unclear the extent to which these effects reflect poor access to quality care in this population, or factors beyond the control of the healthcare system. Dual eligibles and socioeconomically disadvantaged patients are considered in a separate general population PQI literature review<sup>2</sup> and are not included here.

### ***Prevalence of PQI conditions in HCBS populations***

#### *People with Intellectual Disabilities*

- Among people with intellectual disabilities, rates of respiratory illness have been reported at 7-44%, with rates increasing with age (Krahn, 2006).
- Cardiovascular disease has been reported to be 8-45%, also increasing with age (Krahn 2006). Cardiovascular disease (CVD) is leading cause of death for the ID/DD population. Unlike the general population, the proportion of deaths due to CVD is not decreasing, possibly due to the increased lifespan for the ID/DD population, among whom CVD is apparent earlier in life than in the general population. Adults with intellectual or developmental disabilities residing in the community are more likely to have CVD than other adults with ID/DD (Draheim, 2006).

#### *People with Mental Illness*

- Higher rates of hypertension, COPD, and asthma have been documented in individuals with bipolar disorder. This may be due to elevated risk factors, as noted under special clinical considerations (McIntyre, 2008).
- Prevalence of type II diabetes may be elevated several fold in individuals with bipolar disorder and schizophrenia, particularly those taking atypical antipsychotic medications. However, the impact of antipsychotic medications on metabolic/glucose control is under debate, with several recent systematic reviews concluding such a link is weak or

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<sup>2</sup> A review of published literature pertinent to the application of the AHRQ PQIs in the general population was recently updated and is available upon request. For more information, contact Sheryl Davies at [smdavies@stanford.edu](mailto:smdavies@stanford.edu).

inconclusive (Ramaswamy, 2006; Barnett, 2007; Bushe and Leonard, 2007; Citrome, 2007; Newcomer, 2007; Salokangas, 2007; McIntyre 2008).

### ***Clinical considerations for PQI conditions in HCBS populations***

- In addition to general clinical considerations, we also searched for evidence that would inform considerations for including the first admission before the diagnosis of the chronic illness, but found no related review articles.

#### *People with Intellectual and Developmental Disabilities*

- People with intellectual disabilities have been shown to have high rates of comorbidities such as epilepsy, fractures, skin conditions, obesity and sensory loss that may increase need for admission for medical disease. Also, almost half of people with ID are medicated for behavioral problems; a vast majority take multiple medications, with nearly a quarter reporting seven or more medications. People with intellectual disabilities living in the community are more likely to smoke, drink, be inactive or obese than those in institutionalized settings (Krahn 2006).
- Individuals with CHF and cognitive impairment tend to have more severe disease (lower left ventricular ejection fraction) than patients without cognitive impairment (Polidori, 2006).
- Community-dwelling individuals with mild to moderate intellectual disabilities have high rates of CVD, greater morbidity and mortality and risk factors than those in institutional settings (Draheim, 2006).

#### *People with Mental Illness*

- People with severe mental illness treated with atypical antipsychotic medications may experience rapid weight gain, central weight gain, insulin resistance, hypertension, cardiovascular disease, blood dyscrasias and infection as a result of pharmaceutical treatment (Salokangas, 2007; Goddard, 2008; McIntyre 2008).
- Individuals with bipolar disorder have been noted to have higher rates of cardiometabolic disease, neurologic and infectious disorders. Risk factors for chronic disease such as immobilization, trauma, hypercoagulability, drug use, obesity, inactivity, and smoking are also elevated in these individuals (McIntyre 2008).
- Individuals with schizophrenia have elevated rates of poor physical function and pain than the general population (Salokangas, 2007).

### ***Impact of poor clinical care on PQI conditions in HCBS populations***

Clinical care includes coordination, access, education, pharmaceuticals, and tracking/monitoring.

- To date, no evidence has been located specifically linking quality of care for people with developmental disabilities or severe mental illness with admissions for PQI conditions. Evidence related to elderly individuals and dual eligibles is included in a separate general population PQI literature review<sup>3</sup>, which reviewed issues of age, income and socioeconomic status.

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<sup>3</sup> A review of published literature pertinent to the application of the AHRQ PQIs in the general population was recently updated and is available upon request. For more information, contact Sheryl Davies at [smdavies@stanford.edu](mailto:smdavies@stanford.edu).

*People with Intellectual or Developmental Disabilities*

- There is evidence of under-reporting of medical and psychiatric comorbidities by caregivers of individuals with intellectual disabilities. Studies have found that people with ID receive less preventive care than the general population (Krahn 2006).
- People with ID living in the community (alone or with others) were less likely to have access to a physician and to have a normal body mass index than those in group homes or institutions. Caregivers have expressed concern about the lack of physician knowledge of intellectual disabilities, clinicians' reliance on the caregivers during hospitalization, and unavailability of services locally (Krahn 2006; Goddard 2008).

*People with Mental Illness*

- One study noted that individuals with schizophrenia seek care more often than the general population. However, barriers to care include the "attitudes of medical practitioners" and potential underdetection of medical disease by caregivers (Salokangas, 2007).

***Impact of poor self care on PQI conditions in HCBS populations***

Self care includes factors such as adherence to clinical recommendations, diet, and smoking.

*People with Intellectual or Developmental Disabilities*

- Individuals with intellectual or developmental disabilities living in the community have higher rates of smoking, obesity, poor nutrition, and inactivity and are less likely to have current tuberculosis tests and flu vaccines than those living in institutional settings (Krahn 2006).
- Individuals with Down syndrome have higher rates of risk factors for CVD, including higher body fat and cholesterol, but have lower risk based on low blood pressure and endocrine abnormalities. A vast majority of individuals with Down Syndrome are overweight (Draheim, 2006).

*People with Mental Illness*

- Individuals with schizophrenia have been noted to have high rates of smoking, alcohol consumption, poor nutrition, and inactivity (Salokangas, 2007).
- Individuals with schizophrenia and severe mental illness demonstrate high rates of poor adherence to prescribed therapy (Salokangas, 2007; Velligan, 2009).

***Evidence related to exacerbations of PQI conditions in HCBS populations***

- We searched for information related to the frequency of exacerbation of PQI conditions in HCBS populations but found no related review articles.
- We also searched for information related to admissions for exacerbation of PQI conditions in HCBS populations, but again found no related review articles.

***Factors impacting hospitalization for PQI conditions in HCBS populations***

- We found no review articles related to differences in threshold for admission for PQI conditions in HCBS populations.
- We also found no review articles related to the impact of short-stay units or emergency department practice patterns on PQI admissions in HCBS populations.

*People with Intellectual Disabilities*

- In the ID population, medical comorbidity, younger age and rehabilitation need have been associated with inpatient care (Krahn 2006).

#### *People with Mental Illness*

- Two studies from outside the U.S. examined the impact of comorbid depression on hospitalization for COPD. One study reported a higher rate of hospital admission for COPD in patients with depression (Xu, 2008). A second study found no effect of depression on COPD admission rate, but reported longer length of stay in the group with comorbid depression (Ng, 2007).
- Three studies examined the impact of comorbid depression on hospitalization for asthma. A German study found that individuals with depression experienced a 6-fold increased risk of hospitalization for asthma, after adjusting for asthma severity, medication use, adherence to guidelines, gender and age (Schneider, 2008). A second study found that current depression was associated with higher admission risk in patients with a history of asthma, but this effect disappeared after adjusting for SES, physical functioning and obesity. In a third study, lifetime history of depression was not associated with higher risk of asthma admission (Wainwright, 2007).
- One study found that individuals with CHF and depression had a higher risk of readmission at one year, independent of disease severity (Jiang, 2001).
- One small Japanese study identified a high rate of dehydration in severely mentally ill individuals admitted involuntarily (Hatta, 1998).

#### **Documentation and coding of PQI conditions in HCBS populations**

- See the separate general population PQI literature review for details of sensitivity and specificity of physician documentation and ICD-9-CM diagnosis codes related to the PQIs.<sup>4</sup>

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<sup>4</sup> Contact Sheryl Davies at [smdavies@stanford.edu](mailto:smdavies@stanford.edu) for a copy of that review.

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## **Intentional Injuries Inflicted by Others: Assault and Abuse**

For the purposes of this review, we sought information on abuse, assault and neglect for three specific HCBS populations: (1) elderly individuals, (2) people with intellectual disabilities and (3) people with physical disabilities. When available, we also include information on other potential HCBS populations.

### ***Prevalence of abuse for HCBS populations***

- One Texas survey of reported abuse in adults found 62 to 65% were in older adults, 41 to 46% had a physical disability, and 19 to 25% had an intellectual or developmental disability. More than 75% also experienced self-neglect (Pavlik, 2001). In 2000, a survey conducted by the National Center on Elder Abuse of state adult protective services (APS) administrators discovered 4150 cases of sexual abuse in elderly individuals (Hanrahan, 2005).
- Most review articles focused on abuse in older adults. We found only a very limited number of review articles for people with mentally illness or intellectual or developmental disabilities.

### ***Elderly Individuals***

- Abuse of elderly individuals may become evident in a variety of ways, including traumatic injury, social, psychological or cognitive dysfunction, self-neglect, accelerated physical or mental decline, or vague medical complaints. Types of abuse include abandonment, exploitation, physical abuse, financial abuse, sexual abuse, psychological abuse, and neglect (Cooper, 2008). Neglect can lead to pressure sores, dehydration or malnutrition (Fulmer, 2002; Dong, 2005; Lindbloom, 2007). Clinical findings that are highly suspicious in children (e.g. specific fracture types), may be spontaneous and unrelated to abuse in older adults (Lindbloom, 2007).
- Estimates of the prevalence of abuse in elderly individuals ranged between 3% and 30% (Cooper, 2008). One study of the Medicaid Waiver population in Iowa found 2% self-reported physical abuse, 1% psychological abuse, and 7% neglect (Buri, 2006). Other studies of the general population of older adults noted higher rates of psychological abuse (nearly one quarter) and similar rates of physical abuse (1%).
- Of those older adults presenting to the emergency department, around 20% screen positive for neglect (Fulmer, 2002). Additional estimates state that over 2 million older adults are mistreated each year (physical abuse, verbal abuse, and neglect are most common), with a cited prevalence rate of 32 abused individuals per 1000 population (Gorbien, 2005). In 1996, a study by the United States Administration on Aging found that 551,011 persons over age 60 were abused, neglected, or self-neglected in a one-year period (Gorbien, 2005). General population studies found that 6% of older people reported significant abuse in the last month; nearly one quarter reported significant levels of psychological abuse (Cooper, 2008).
- More than 40% of older adults who were abused and neglected were aged 80 years or older. Alleged perpetrators included adult children (32.6%), other family members (21.5%), or spouse/intimate partners (11.3%) (Abbey, 2009).

### ***People with Intellectual or Developmental Disabilities***

- A survey of health professionals working with children and youth with intellectual disabilities (ID) judged 11.5% of them to have experienced maltreatment based on behavior and physical evidence, compared to 1.5% of a control group of 403 children and youth without disabilities. Maltreatment was most prevalent among children with behavior disorders (approximately 53%), speech or language disorders (approximately

36%), intellectual disabilities (approximately 28%), and health-related disabilities (approximately 28%) (Horner-Johnson, 2006).

- One study found that 33% of a sample of 80 people with ID said they had experienced unwanted sexual contact, compared to 23% of a sample of students without disabilities (Horner-Johnson, 2006).
- A study of hospital charts and parental interviews in a sample of 87 adolescent females with intellectual disabilities revealed that 25% had been sexually abused, including a 10% rate of incest. (The review article citing this study indicates that 25% may in fact be an underestimate as a result of a strict definition of sexual abuse being used in the study.) Approximately one third of the sample had a mild disability, 26% had a moderate disability, and 9% had a severe disability (Tharinger, 1990).

#### *People with Physical Disabilities*

- In one study, 25 of 31 women with physical disabilities (nearly 81%) reported experiencing abuse, including 11 (35.5%) women who reported sexual abuse. Another study reported that women with and without disabilities did not differ significantly in the proportions that had experienced emotional (51.7% versus 47.5%), physical (35.5% versus 35.6%), or sexual abuse (39.9% versus 37.1%), but women with disabilities had experienced abuse for significantly longer periods of time than women without disabilities (Horner-Johnson, 2006).

#### *Other Vulnerable Populations*

- In a survey of people receiving home assistive devices, 30% of the respondents reported one or more types of maltreatment from their primary personal assistance provider, while 61% reported one or more types of maltreatment from other personal assistance providers. Substantial proportions of the respondents had experienced verbal abuse from their primary personal assistant (18%) or other personal assistants (29%). In addition, 6% had been neglected by their primary personal assistant and 26% had other personal assistants neglect their needs. Ten percent experienced physical abuse and 3% said their primary personal assistants had sexually abused them (Horner-Johnson, 2006).

#### ***Clinical considerations for abuse in HCBS populations***

- Neglect most commonly affects individuals who are in poor health, are poorly functioning, live alone, or are generally dependent on others for care. This creates a cycle of progressive inability to perform activities of daily living (ADLs) as the result of mistreatment and increases the risk for additional incidents of abuse and neglect (Dong, 2005).

#### *Elderly Individuals*

- Risk factors for abuse and neglect of elderly individuals include: low socioeconomic status (SES), minority status, cognitive impairment, increasing age, functional decline, personality disorders, isolation, and excessive use of alcohol or drugs. A recent study also found a high correlation between dementia and depression with abuse and neglect of elderly persons (Harrell, 2002). This extent of physical impairment does not necessarily affect the likelihood of abuse or neglect in older adults (Abbey, 2009). Elderly people facing abuse and neglect sometimes react with denial, resignation, withdrawal, fear, submissiveness, or depression. These reactions can result in feelings of guilt, shame, helplessness, worthlessness or “learned helplessness.” (Dong, 2005)

- Mortality rates resulting from abuse of elderly individuals have been found to be as high as 50% over a 4-year follow-up period (Cooper, 2008). Mortality in older adults has been associated with inadequate staffing levels in care homes, lack of supervision, a lack of ethnically sensitive food options, and premature use of liquid or pureed food diet in order to compensate for lack of staffing.
- Abuse of elderly individuals is a risk factor for their placement in nursing home and elderly individuals experiencing abuse are at greater risk for reporting other serious health problems in addition to abuse (Abbey, 2009).

*People with Intellectual, Developmental or Physical Disabilities*

- One study estimated that people with disabilities are between 2 and 5 times more likely to be maltreated than people without disabilities and that children with disabilities are at 4 to 10 times greater risk for maltreatment than children without disabilities (Horner-Johnson, 2006). People with disabilities are subject to the same types of maltreatment as people without disabilities, but having a disability can also put individuals at risk for unique forms of maltreatment related to their impairment or accommodation needs (e.g., withholding of adaptive mobility or communication devices as a way of controlling and isolating a person with a disability) (Horner-Johnson, 2006).
- People with physical or intellectual disabilities are at increased risk for abuse or neglect due to their lifelong dependency on caregivers (compared to elderly individuals who are often only dependent on caregivers later in life). Individuals with disabilities often may not question the care they receive at the hands of others (particularly those with intellectual disabilities), and therefore are at increased risk for prolonged exploitation. There is also very little information or education on sexual abuse adapted for people with intellectual disabilities, which can undermine efforts at prevention (Tharinger, 1990).

***Factors impacting hospitalization for abuse among HCBS populations***

*Propensity to Present or Disclose Abuse Among HCBS Populations*

Our search of the available literature identified a number of factors related to the propensity to present or disclose abuse.

Gender

- Neglect in women seems to be more often reported than neglect in men, although this may be confounded by the fact that women are at greater risk for neglect and abuse by others. One study found that women are 40% to 300% more likely than men to be reported as abused or neglected, depending on the age group (Pavlik, 2001).

Age

- In cases in which abuse or neglect of elderly people was identified, 16% of individuals refused services (Abbey, 2009). However, a study of urban emergency department (ED) use found that abused and neglected community elders recognized through a state elderly protective services program were more likely to visit the ED for assessment and treatment (Dong, 2005).
- One study reported that only 1 in 14 cases of elder abuse came to the attention of medical authorities (Dong, 2005). There was a 150% increase in reporting of elder abuse from 1986 to 1996. It has been estimated that in 1988 there were 140,000 reports of elder abuse and that by 1996 that number had reached 293,000. Mistreatment of elderly individuals is still underreported (Gorbien, 2005).

### Cultural Differences

- Cultural differences can affect perceptions of abuse and neglect. One study found that people from different ethnic backgrounds interpreted the same scenarios of possible abuse or neglect differently, though extremes of abuse were apparent regardless of ethnicity (Abbey, 2009). Another study of black, white, and Korean American subjects showed differences in perceptions of abuse and neglect and in help-seeking patterns. Korean Americans were much more tolerant of abusive situations and less likely to seek help. They did not want to reveal “family shame” to others or create conflict among their relatives (Dong, 2005).
- A study of ED presentations found that older adults who are assessed as more frail, dependent, and isolated and who show physical signs of neglect are more likely to be identified as having been neglected (Fulmer, 2005).

### Disability

- One study reported that 1 in 30 cases of sexual abuse in persons with disabilities is reported, compared to 1 in 5 cases in non-disabled populations (Tharinger, 1990).

### *Frequency of Admission for Abuse*

- Two studies indicated that one third of emergency department visits by older adults who had been abused or neglected resulted in admission (Lachs, 1997; Dong, 2005).
- A 7-year longitudinal study of 182 elderly individuals who were abused found that 628 physician visits were made as a result of abuse, 30.6% of which resulted in hospitalization (Fulmer, 2002).
- In one study with a small sample population, 41.2% of elderly individuals that experienced abuse were admitted to the hospital. Hospitalization was due to injury (including dehydration) in 17.6% of those cases (Cham, 2000).

### *Differences in Threshold for Admission by HCBS Population, Practice Patterns or Socioeconomic (SES) Factors*

- Older individuals of low-income/low-SES may be more likely to present to an emergency department, rather than a primary care physician. This might limit the likelihood that their symptoms are recognized as being a result of abuse and that adequate follow-up occurs (Fulmer, 2005).

### *Impact of Short Stay Units or Emergency Department Practice Patterns on Admission Rates*

- No related review articles

### ***Evidence of interventions to reduce the rate of hospitalizations for abuse***

- We found no evidence to date linking interventions with decreases in hospitalizations for abuse or neglect. However, several studies have identified interventions for caregivers and staff of long-term care facilities that reduced overall reported or self-reported abuse and which may prevent future or recurrent abuse (Lindbloom, 2007).
- Interventions that can apply to all populations included: referral to Adult Protective Services (Harrell, 2002), court protection plans, referral to social workers, context-specific interventions, patient education on the occurrence of abuse, support groups, and placement in a safe home (Abbey, 2009).

### *Elderly Individuals*

- Some reviews of elder abuse have found that improving screening for abuse through education, tools, and expert teams may increase the proportion of abuse cases identified. Therefore, lower reported rates of abuse and neglect may not reflect less abuse/neglect in the population, but rather under-detection. In some cases higher rates of reported abuse may reflect better detection of underlying abuse and neglect (Fulmer, 2002; Dong, 2005). However, it is unclear how this might impact the overall rate of hospitalization in a state (McInnes, 2004).
- Specific interventions used in preventing elder abuse are SANE (Sexual Assault Nurse Examiners) and CARIE (Coalition of Advocates for the Rights of Infirm Elderly), both of which involve education and training in recognizing and assessing abuse of elderly individuals. Seminar-based education was found to be more effective than written material. Training for providers related to stress management and conflict resolution reduced reports of abuse by 24% to 55% in nursing home settings (Lindbloom, 2007).
- Physician training, such as clinical electives in geriatrics and continuing medical education courses, in the detection of abuse is necessary, particularly given the underreporting of abuse due to lack of knowledge of definitions and reporting protocols (Dong, 2005).

#### *People with Intellectual, Developmental or Physical Disabilities*

- To prevent abuse and maltreatment among individuals with disabilities, health educators need to be aware of maltreatment as a major health issue and provide training to help individuals protect themselves. Increased awareness and training among law enforcement and disability service providers is also essential. Reducing stigma and negative attitudes against people with disabilities may also help combat abuse, (Horner-Johnson, 2006).

#### **Documentation and coding of abuse in HCBS populations**

##### *Identification, Documentation and Coding of Admissions Resulting from Abuse*

- We identified several studies that examined the identification of abuse by outpatient or emergency room physicians. All these studies noted that ED clinicians under-identify and under-report abuse cases (Fulmer, 2002; Gorbien, 2005).
- One major source of variation in the identification of abuse is differing interpretations of the terms “abuse” and “neglect,” which may vary geographically. For instance, some people may consider excessive use of restraints to be abuse, or failure to provide ethnically sensitive food resulting in weight loss to be neglect. Some of these events may result in hospital admission, and providers may differentially interpret (and code) these events as abuse or neglect (Lindbloom, 2007).
- Most cases of abuse (98-99%) are not reported or identified as such, and are unlikely to be coded (Fulmer, 2002; Dong, 2005; Cooper, 2008). One quarter of ED visits related to abuse had ICD-9 codes consistent with injury, and 66% of the individuals who used emergency services had at least one ED visit with injury-related discharge diagnosis or chief complaint (Dong, 2005).
- The most common individuals responsible for reporting the abuse of older adults were family members (17%), social services (11%), friends/neighbors (8%), self (6%), long-term care staff (6%), law enforcement (5%), and nurses/aides (4%). Physicians constituted only 1% of abuse reporters (Abbey, 2009).

##### *Detection and Screening for Abuse in HCBS Populations*

- In outpatient medical practices, symptoms of individuals presenting with injuries resulting from abuse are often treated, but the underlying abuse and neglect is not discovered. Those patients often have nonspecific presentations to the outpatient settings which can make identification difficult (Dong, 2005).

#### By Physicians

- Physicians report only a small portion of all cases of abuse and neglect of elderly individuals. One survey found that physicians ranked 10<sup>th</sup> among health care professionals and paraprofessionals in assisting identification of elder abuse and neglect. Over a 10 year period, of the more than 50,000 cases reported to the adult protective services in Connecticut, physician reporting accounted for less than 1.5% (Dong, 2005; Abbey, 2009). Barriers to clinicians' reporting of abuse and neglect include lack of knowledge of laws regarding abuse, concern over angering the abusers, the possibility of court appearances, and possible damage to relationship with patients (Abbey, 2009).
- There is a lack of awareness among physicians about reporting abuse of elderly individuals. In a 1987 study in Alabama, only 24% of the responding physicians were aware of the channels of reporting abuse cases. Only 31% of physicians reported having a written protocol for the reporting of elder abuse and neglect, and they were generally not familiar with applicable state laws. Only 25% of physicians were able to recall educational content related to abuse and neglect of elderly individuals during their residencies (Dong, 2005).
- We did not identify any review articles addressing physician reporting of abuse or neglect of other HCBS populations.

#### In Emergency Departments

- In a 2-year study of emergency departments in Florida and New York, ED screeners identified neglect in 5% of cases, while a neglect assessment team identified neglect in 22% of the same cases. This markedly different rate of neglect suggests that screening for neglect in the ED is important but likely underestimates the true number of cases of neglect (Fulmer, 2005). This could be attributed to lack of continuity in care, overburdened EDs, or a lack of training among ED personnel in identifying abuse and neglect.

#### *Additional Coding Considerations*

- Although codes for adult maltreatment include a code for the injury associated with the abuse code, Coding Clinic has clarified that these codes may be used independently.

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## Medication Errors

This candidate HCBS quality indicator focuses on errors in administration of medication (wrong drug, wrong dose, wrong time, wrong person). Within the literature, information about these types of events is typically included under Adverse Drug Events (ADEs), which include errors in administration as well as adverse events arising from correct administration of medication. We reviewed the ADE literature with respect to HCBS populations and, when possible, focused specifically on ADEs related to errors in administration of medication. Relevant review articles identified by our search typically focused on ADEs in particular settings (i.e., home health care, inpatient, long-term care), rather than in particular populations. Therefore, we did not organize this section by HCBS population. We focused primarily on studies in the home health care setting, and include some information from other settings for comparison, when relevant.

### ***Prevalence of Adverse Drug Events in HCBS populations***

#### *Home-health Care Population*

- Patients discharged to home health have similar, or possibly higher, risk of ADEs as those discharged to long-term care, based on risk factors known to be associated with serious ADEs that result in emergency room visits, hospitalization, or death. The authors conclude that patients discharged to home health care may need additional medication assistance (Triller, 2005).
- Authors of a Japanese study of community-dwelling elderly individuals eligible for their home-care insurance program report that individuals who reported needing but not receiving help with medication management were significantly more likely to experience all-cause hospitalization (Kuzuya, 2008).

#### *Long-term Care Population (for comparison)*

- In one study of drug administration errors in 510 residents of an assisted living facility, the rate of medication errors was 28.2% (N=1,373 errors observed), but only 3 cases were determined to be clinically significant. The errors were attributed to wrong time (70.8%), wrong dose (12.9%), omitted dose (11.1%), extra dose (3.5%), and others (Young, 2008).
- In another study of 23 long-term care facilities 2,731 errors in drug administration were observed. Of these, 47% occurred during administration, including dose omission (32%), overdose (14%), and underdose (7%). Nearly half of errors (48%) were attributable to human error. Eight percent of errors resulted in a serious event requiring monitoring or intervention (Pierson, 2007).

### ***Clinical considerations of Adverse Drug Events in HCBS populations***

- A number of nursing home and staff characteristics are associated with increased risk of ADEs or hospitalization, including general staff burden (Aufseeser-Weiss, 2001), hours worked consecutively, including on-call (Aufseeser-Weiss, 2001), inattention to patient history related to adverse reaction to properly administered drugs (Cooper, 1999), and potentially inappropriate medication prescribing (Lau, 2005).
- One study found that risk of ADEs was highest during the stages of ordering and monitoring medication, rather than during the processes of dispensing, transcribing or administering it. "Monitoring" included inattention paid to signs or symptoms of drug toxicity such as lab results and clinical findings (Gurwitz, 2000).

### ***Evidence for prevention of Adverse Drug Events in HCBS populations***

- Reminder strategies for patients and nurses have been shown to improve medication recognition and independence in taking medications, but these studies did not link such outcomes to ADEs or hospitalization (Feldman, 2005; Shearer, 2009).
- Pharmacist intervention in home-care setting may detect inappropriate dosage or drug therapy, noncompliance, or inadequate monitoring, but such intervention did not translate into fewer emergency department visits or hospitalizations (Triller, 2007; Delate, 2008).
- One literature review of interventions to provide clinical pharmacy services in the home (of which the home-care population was considered 1 of 3 home-based populations included in the review), identified 57 different home-based programs in the U.S. and abroad, published in 66 reports over the last 3 decades. Of 21 randomized controlled trials, 13 found a difference in outcomes due to the intervention. However, interventions decreased hospitalization rates in only 3 of the 10 studies that reported hospitalization as an outcome (MacKeigan, 2008).
- In a systematic literature review of randomized controlled trials including the use of a pharmacist to reduce unnecessary polypharmacy in elderly individuals, Rollason and co-authors (Rollason, 2003) reported that few of the 14 articles identified focused on rate of hospitalization as a consequence. Of the three that did, only one showed a reduction in hospitalization associated with reduced number of medications (Rollason, 2003).
- In a review of the literature pertaining to computerized physician order entry systems with clinical decision support, half of the studies identified (5 of 10) reported a significant reduction in ADEs in inpatient settings. The authors identified no articles in the long-term care setting (Wolfstadt, 2008).

#### ***Factors impacting hospitalization for Adverse Drug Events in HCBS populations***

- Most ADEs in the home health care population do not result in hospitalization. In a study of 256 elderly patients discharged after a medical illness, 52 participants experienced 64 ADEs, but only one resulted in hospitalization (Gray, 1999).
- One large, nationally-representative study reported that 12% of emergency department visits for ADEs related to commonly-used analgesics resulted in hospitalization (Willy, 2009).

#### ***Documentation and coding of Adverse Drug Events in HCBS populations***

- In a commentary on developing a drug adverse events classification system for home care-specific events, Audette et al. (2002) discussed their position that the terminology to describe these events comes from the inpatient setting and does not accurately represent many drug-related problems that arise in the home-care setting (Audette, 2002). The authors provided the examples of individuals who cannot afford their medications, lack transportation to pick up medication, or who do not wish to take the medication. The authors assert that inpatient-based problem descriptions, such as 'indication without drug therapy' or 'patient not receiving drug' are too broad to clearly identify the problem. They developed a classification scheme specific to the home health care setting, although this is not widely used and is not included in administrative data.

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## **Pressure Ulcers**

We sought information on pressure ulcers in key HCBS populations, in particular elderly individuals and individuals with physical disabilities or limited mobility. We included information on other relevant populations, when identified.

### ***Prevalence of pressure ulcers in HCBS populations***

#### *Elderly Individuals*

- The prevalence of pressure ulcers has been estimated at 15% among elderly individuals who are hospitalized (Bates-Jensen, 2007). Approximately 70% of pressure ulcers occur in individuals over the age of 70 years (Garcia, 2006).
- 42% of elderly individuals undergoing hip fracture repair experience PU, individuals with neurological disorders have a 25 to 85% lifetime risk of PU, and 2.5% of people in long-term care develop PU (Dharmarajan, 2003; Garcia, 2006).

#### *Individuals with Physical Disabilities or Limited Mobility*

- Individuals who cannot get out of bed may form pressure ulcers in as little as 1 to 2 hours, whereas those who use wheelchairs and who cannot move voluntarily may form pressure ulcers in even less time because of the greater relative force on their skin (Bates-Jensen, 2007). The prevalence of ulcers increased by 28% (Dharmarajan, 2003) in individuals limited to a chair or bed for one week.
- Epidemiological studies indicate that, in the US and Canada, pressure ulcer prevalence is 33% in individuals with spinal cord injury (SCI) living in the community (McInnes, 2008). In the US only, annual incidence rates of PU in people with SCI range from 20% to 31% and prevalence rates from 10.2% to 30%. One quarter of pressure ulcers in people with SCI are classified as severe (stage III or IV) (Caliri, 2005; Raghavan, 2003; Regan, 2009). Pressure ulcer recurrence has been reported to be as high as 35% for people with SCI (Caliri, 2005).

### ***Predisposing conditions for development of pressure ulcer in HCBS populations***

- Prior development of pressure ulcers results in a 10-fold increase in the risk for additional ulcers (Dharmarajan, 2003).
- Pressure ulcer prevalence is greatest in individuals considered underweight by body mass index (BMI). People who are overweight and obese had lower PU prevalence. However, as BMI increased, the prevalence of higher stage PU increased, suggesting that high BMI may be associated with delay in detection or treatment of pressure ulcers (VanGilder, 2009).

#### *Elderly Individuals*

- Protein-calorie malnutrition is a major risk factor for pressure ulcers (PU) and has been reported in 15% of older adults living in the community, up to 62% of hospitalized patients, and up to 85% of nursing home residents (Garcia, 2006).

#### *Individuals with Physical Disabilities or Limited Mobility*

- Limited mobility caused by hip fractures, gait abnormalities, progressive neurologic disorders, and skin changes conducive to abnormal breakdown are all more prevalent in older adults than in the general population, placing them at higher risk for pressure ulcers (Garcia, 2006).
- Individuals with spinal cord injury have neurologically impaired skin which decreases skin adaptability and elasticity, thus resulting in increased risk for pressure ulcers (Caliri, 2005).

*Special Considerations for Prevention or Clinical Management*

- The incidence of new lesions varies widely according to clinical situation; the highest rates are found in elderly individuals undergoing orthopedic procedures (9–19% incidence) and people with quadriplegia (33–60% incidence). In nursing homes, prevalence estimates vary from 2% to 24%. In home healthcare settings, the prevalence of pressure ulcers has been estimated to be 6% to 9%. In outpatient settings, the prevalence of pressure ulcers is estimated to be 1.6% (Bates-Jensen, 2007).
- Physical restraints, sometimes used in people with psychological disabilities, increase the risk for PU development (Comondore, 2009).
- Pressure ulcer prevalence is greatest in patients in long-term acute care (29-30%), followed by rehabilitation (16.2-19.3%), and acute care (13.3%) (VanGilder, 2009).

***Impact of poor self care on pressure ulcer development***

- Poor skin care, particularly the inability to minimize moisture including incontinence and to keep skin clean and dry, is associated with increased risk for pressure ulcer development in immobile and otherwise at-risk individuals (Caliri, 2005; Dharmarajan, 2003; Gorecki, 2009; Regan, 2009).
- One review noted that there is a subset of people who experience recurrent pressure ulcers because of non-adherence to recommended prevention strategies. This may be due to the fact that individuals with recurrent pressure ulcers may lack incentives to follow prevention behaviors (Regan, 2009).

***Evidence for prevention of pressure ulcers in HCBS populations***

*Prevention of Pressure Ulcer Development*

- Risk assessment for individuals at high risk for developing pressure ulcers should be part of prevention strategies and have been linked to better pressure ulcer outcomes (Bates-Jensen, 2007; Caliri, 2005; Dharmarajan, 2003).
- Multiple studies have emphasized the importance of interventions related to management of tissue load (pressure reduction): use of contoured foam overlays, medical sheepskin overlays, static air, gel-filled, bead-filled support surfaces, Group 3 air-fluidized therapy support, scheduled repositioning, and pressure reducing mattresses (Bates-Jensen, 2007; Dharmarajan, 2003; McInnes, 2008; Reddy, 2006). One review found insufficient evidence to recommend specific turning regimens for people with impaired mobility (Reddy, 2006). Rotating beds did not decrease PU prevalence (Reddy, 2006) and the relative benefits of higher-tech constant low pressure and alternating pressure for prevention are unclear (McInnes, 2008).
- Because of the link between poor diet/protein intake, low serum albumin levels and pressure ulcer development, two reviews suggest that nutritional assessments be used to identify nutritional deficiencies and to develop nutritional support programs. High protein diets (24-25% protein), vitamin/mineral supplementation, and the use of feeding tubes in people with nutritional deficiencies are specifically mentioned as possible support programs (Bates-Jensen, 2007; Caliri, 2005; Dharmarajan, 2003; Reddy, 2008; Reddy, 2006; Regan, 2009).
- At-risk individuals, particularly those at chronic risk (people with SCI or immobility concerns) need more information about causes, risks, prevention, physiological processes, and treatment interventions to prevent PU development or progression.

Education should include information regarding nutrition, pressure redistribution surfaces for the bed and wheelchair, and pressure ulcer etiology. Such information should be provided both verbally and in low-reading level written form (Caliri, 2005; Gorecki, 2009; Regan, 2009). Comprehensive rehabilitation programs and telehealth rehabilitation were shown to be effective in preventing PU development in people with SCI (Caliri, 2005).

- Additional prevention strategies include regular pressure relief every 15 to 30 minutes by performing a lateral bend, forward lean, or vertical push-up; having an individually prescribed wheelchair with a pressure redistribution cushion (and a power or manual tilt/recline feature if manual pressure relief is not possible); decreasing or stopping smoking; limiting alcohol consumption; and monitoring of weight to detect undesirable trends (Caliri, 2005; Regan, 2009).
- Proper skin care and skin assessment is essential as part of both prevention and treatment regimens (Caliri, 2005; Dharmarajan, 2003).

### *Prevention of Pressure Ulcer Progression*

- Pressure ulcers in vulnerable populations should be assessed for location, depth and stage, size, and wound bed (e.g., necrotic tissue, exudate, wound edges for undermining and tunneling, presence or absence of granulation and epithelialization) to help develop effective intervention strategies. For example, changing the rotation of repositioning efforts or seating times may prevent progression of ulcers located on turning or weight-bearing surfaces. Wound depth and size can be predictors of outcome (lower stages have a greater likelihood of healing) (Bates-Jensen, 2007; Caliri, 2005).
- Management of underlying causes of pressures ulcers is likely to more effective than topical or adjunctive therapy in older adults and vulnerable populations (Reddy, 2008).
- The benefits of using specific topical agents vs. simple moisturizers for individuals with impaired skin health is unclear (Reddy, 2006).
- Physicians' ability to interact with patients' in a holistic way, communication about treatments, and teaching patients self-care was indicative of a positive therapeutic environment. Agreement about symptoms and treatment regimen through dialogue and mutual decision-making was important to patients, because it allowed them to regain some control and independence (Gorecki, 2009).
- Electrical or laser stimulation, when combined with pressure management interventions, may serve as effective wound treatment strategies in people with SCI (Regan, 2009).
- Use of anabolic steroids was shown to be effective in improving wound healing in people with impaired nutritional status (Regan, 2009).
- Treatment strategies in geriatric populations should vary according to the stage of ulcer development (I-IV) but should always include prevention regimens, infection control, nutritional assessments, and pain management. Severe cases may require debridement, cleansing with isotonic sodium chloride solution, or surgical repair (Caliri, 2005; Dharmarajan, 2003).

### *Detection and Screening in HCBS Populations*

- Several reviews note that factors such as incompetent health care, inadequate use of equipment, and delays in noticing and treating self-reports of early signs of PU were the major factors contributing to pressure ulcer progression. Providers failed to identify early warning signs for pressure ulcers in at-risk populations (Caliri, 2005; Gorecki, 2009).

### ***Factors impacting hospitalization for pressure ulcer among HCBS populations***

#### *Propensity to Present with Pressure Ulcer*

## Pressure Ulcers

- One study found that pressure ulcers were associated with greater mortality but not more frequent hospitalization (Bates-Jensen, 2007).
- Adequate preventive care can be compromised by a lack of social or financial support (low SES), thus leading to increased risk for development or recurrence of pressure ulcer. Some people, in particular those with spinal cord injury, may also lack the long-term knowledge to successfully handle chronic pressure ulcer risk (Caliri, 2005).
- One review found that primary protective factors for pressure ulcer development were general characteristics (employment, marital status, years of education), not specific health behaviors (Caliri, 2005). This suggests a possible role for SES in determining PU prevalence.

### *Frequency of Admissions for Pressure Ulcer*

- Pressure ulcers are associated with an average length of stay between 10.2 and 14.1 days, depending on age at admission, in comparison with average length of stay for patients without pressure ulcers at 4.6 days (VanGilder, 2009).
- Review articles almost exclusively focus on pressure ulcers developed in hospitals or care facilities (post-admission). No information was available about patients admitted directly as a result of PUs (only as a hospital complication).

### *Differences in Threshold for Admission by HCBS Population, Practice Patterns or Socioeconomic Factors*

- Lower pressure ulcer prevalence was observed in residents receiving care in not-for-profit nursing homes when compared to for-profit nursing homes (Comondore, 2009).

### **Documentation and coding of pressure ulcer in HCBS populations**

#### *Physician Documentation*

- Pressure ulcers may currently be classified using a variety of methods and instruments, many of which have low inter-rater reliability. There is currently insufficient evidence to recommend a specific pressure ulcer classification system for use in daily practice, which could be a barrier to consistent documentation across health care providers and settings (Kottner, 2009).

### *Sensitivity and Specificity of Diagnosis and External Cause of Injury Codes for Pressure Ulcer*

- No information available in review articles.

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## Accidental Injuries Potentially Due to Neglect

We identified a large body of literature addressing falls in the elderly population. Literature on other injuries included within the candidate indicator (burns, poisoning, firearms accidents, drowning, and exposure to heat and cold) was more sparse. This literature typically focused on the general population, although we identified a limited number of reviews specifically addressing injuries among individuals with intellectual or developmental disabilities. In organizing this section, we separated information on falls, and in particular falls in elderly individuals, from information on other injury events in other relevant populations.

### **Prevalence of injury events in HCBS populations**

#### *Falls in Older Adults*

- A large literature exists examining falls among older adults. Prevalence of falls elderly adults living in the community range from 33-50% per year (Kinney, 2004; Chang and Ganz, 2007; Inouye *et al.*, 2007). Falls recur in half of these individuals (Kinney, 2004). Another review reported a rate of 13 falls per 1000 bed-days in populations in care homes (Oliver, 2007).
- Many of these falls result in injury. In care homes, 30% of falls have been reported to result in physical injury and 3 to 5% in fracture. It is unknown exactly how many falls result in hospitalization (Oliver, 2007). Other review articles report serious injury rates (fracture, head injury, hospitalization) of 3 to 10% (Kinney, 2004; Chang and Ganz, 2007; Oliver, 2007) and 30% result in some physical injury.(Oliver, 2007)
- Falls account for a substantial percentage of emergency department visits (10%) and urgent hospitalizations (6%) (Kinney, 2004). Falls account for 90% of hip fractures in the elderly, and are fatal in 12 to 20% of hip fractures (Carter *et al.*, 2001).
- Falls are the leading cause of unintentional injury, which ranks as the sixth leading cause of death, in older people (Inouye *et al.*, 2007).

#### *Other Injuries*

- One review article examined the prevalence of injury in people with intellectual and developmental disabilities. Individuals with intellectual disabilities (ID) have twice the unintentional injury risk of the general population (Sherrard *et al.*, 2004).
- Sherrard and colleagues report that 60% of medically attended injuries in people with ID are due to falls and 7% to burns. In addition, the leading causes of accidental death in people with ID are asphyxia and drowning (Sherrard *et al.*, 2004). Of injuries resulting in hospitalization in this population, 30% are due to falls, 8% to poisoning, 5% to burns, and 2.6% to near drowning. Of injuries resulting in emergency department visits, 38% are due to falls and 5% to burns. Of injuries resulting in presentation to primary care practice, 30% are due to falls and 3% to burns (Sherrard *et al.*, 2004). Injury patterns in people with intellectual disabilities are similar to that of young children in the general population. Seventy-five percent of injuries to people with ID occur in the home (Sherrard *et al.*, 2004).
- In the general US population in 1990, 12,400 persons died from falls, 5200 from drowning and 4300 from burns. (Hingson and Howland, 1993)
- Prevalence of accidental injury in people >65 years (average deaths per year 1994-1998 in Wisconsin) (Cox *et al.*, 2001)
  - Falls: males=171; females=217
  - Burns: males = 11; females = 8
  - Poisoning: males = 7; females = 7
  - Drowning: males = 6; females = 3

## Accidental Injuries

- Injuries are fatal in some cases, and it is unclear how many of these fatalities will first present to a hospital. Rates of fall death were highest for older adults, poisoning deaths were highest among middle-aged adults, and fire/burn death rates were highest among children. Inhalation/suffocation and drowning deaths were important injury issues for young children. (Runyan *et al.*, 2005)
- Home injury deaths varied by age and gender, with males having higher rates of home injury death than females (8.78 vs 4.97 per 100,000), and older adults ( $\geq 70$  years) having higher rates than all other age groups. Falls (2.25 per 100,000), poisoning (1.83 per 100,000), and fire/burn injuries (1.29 per 100,000) were the leading causes of home injury death. The highest death rates due to unintentional injuries were among people aged 80 years or older (47.91 deaths per 100,000, 95% CI 46.41– 49.40), followed by those aged 70 to 79 (14.57 per 100,000 deaths, 95% CI 13.97–15.61). (Runyan *et al.*, 2005)
- From 1992 to 1999, an average of 7,674 adults aged  $>60$  years died each year as a result of home injury. Falls were the leading cause of home injury death, accounting for 48.8% of the deaths for adults aged 60 to 69, and 65.9% of the home injury deaths for adults aged  $>70$ . Fire injuries were the second leading cause of home injury death across all older adult age groups. (Runyan *et al.*, 2005)
- Rates of home injury death among older adults increased substantially with age. Adults aged 70 to 79 were more than twice as likely to die due to an injury in the home as were adults aged 60 to 69; the home injury death rate for those  $\geq 80$  was more than six times that of the 60 to 69 age group. The ratio of home injury deaths for older males versus older females decreased as age increased, from 1.9:1 at 60 to 69 to 1.4:1 at  $> 80$ . Of the causes identified, 16.8% of deaths were due to falls on or from stairs or steps; 6.6% from slipping, tripping, or stumbling; and 3.3% from falls from a chair or bed. (Runyan *et al.*, 2005)

### *Heat-related Injury*

- Elderly individuals hospitalized for heat stroke during the 1995 Chicago heat wave experienced a 21% mortality rate (58 people hospitalized, mean age 67.5 years). Those patients experienced multi-organ dysfunction with neurological impairment (100%), moderate-to-severe renal insufficiency (~50%), disseminated intravascular coagulation (45%), and acute respiratory distress syndrome (10%). (Donaldson *et al.*, 2003)

### *Burns*

- One review reported an annual rate of 5.4 deaths from burns per 1000 population for persons aged  $>65$  years (compared to 4.8 for children  $< 5$  and 1.5 for persons aged 5-64), although these data are no longer current. (Hingson and Howland, 1993)
- Fire/burn injuries were found to have a rate of 1.29 per 100,000 in elderly populations (Runyan *et al.*, 2005)

## **Clinical considerations for injury events in HCBS populations**

### *Falls*

- Risk factors for falls in older adults include impaired gait and balance, weak lower-limb muscles, poor vision, use of psychotropic medications or multiple medications, specific medical conditions (Parkinson's disease, stroke, osteoarthritis of lower limbs, epilepsy), sensorimotor deficits, impaired reasoning, and reduced capacity to cope with environmental challenges. (Cumming, 2002; Kinney, 2004; Sherrard *et al.*, 2004; Chang and Ganz, 2007; Harlein *et al.*, 2009).

- People with dementia have a two- to three-fold relative risk of falls compared to cognitively healthy populations and a tripled to quadrupled risk of sustaining injuries as a result of falls. The annual incidence of falls among people with dementia is 60-80% (Harlein *et al.*, 2009).
- The risk of falling increases as the number of risk factors increases (from 8% with no risk factors to 78% among those with 4 or more risk factors) (Kinney, 2004). Between 65% and 100% of elderly individuals with 3 or more risk factors experienced a fall in a one-year observation period. (Chang and Ganz, 2007)
- Age is a major risk factor for falls (one third of those experiencing falls are >65 years old and half are >80 years old) (Chang and Ganz, 2007). Thirty percent of fall deaths occur in patients over age 85 (who account for only 1% of the population (Hingson and Howland, 1993). Age-related changes in the somatosensory, vestibular and visual systems, which contribute to the maintenance of balance, and age-related changes in muscle and bone are likely to contribute to an increased risk of falls in this population (Carter *et al.*, 2001). In addition, overall muscle strength and mass decline 30 to 50% between the ages of 30 and 80. As a result of the changes in muscle and sensory function, 46% of adults 85 years and older and 36% of adults over 75 years report postural disturbances compared with 13% of those aged 65 to 69 years. Muscle mass and function are important for stability and correct balance, and are also thought to give some protection to the proximal femur by attenuating the hip-impact forces that occur in sideways falls in older adults (Carter *et al.*, 2001).

### *Other Injuries*

- We found little review literature examining non-fall injuries in HCBS populations. Cold is a risk factor for cardiovascular disease (CVD) mortality. Older adults account for the majority of CVD deaths and are therefore at increased risk for complications of cold exposure, largely because the ability to regulate body temperature deteriorates with age (Mercer, 2003). Almost any drug that impairs central nervous system activity, cardiovascular reserve, or body hydration can reduce heat tolerance; such drugs are used commonly in older populations (Donaldson *et al.*, 2003).
- We did not find review articles examining clinical considerations for other injuries in other subpopulations.

### **Evidence for prevention of injury events in HCBS populations**

#### *Falls*

- Several strategies have been documented to reduce fall risk in older adults, including previous fall documentation and thorough risk assessment (Chang and Ganz, 2007), as well as use of assistive devices in those with poor balance and mobility (McInnes and Askie, 2004; Chang and Ganz, 2007). Other strategies that have been shown to be effective in reducing fall risks in older adults include: exercise programs (particularly those focusing on strength and flexibility training), exercise education, gait examination (Carter *et al.*, 2001; Cumming, 2002; Kinney, 2004; McInnes and Askie, 2004; Chang and Ganz, 2007), home modification (McInnes and Askie, 2004), prevention education (including community health) (Cumming, 2002; McInnes and Askie, 2004; Inouye *et al.*, 2007), risk amelioration (e.g. eyesight checks, medication review, footwear modification, wheelchair repairs, reduction of medication use) (Cumming, 2002; McInnes and Askie, 2004), and home visits by occupational therapists (Cumming, 2002).
- Interventions that included 1) development of walking/transferring skills with an occupational therapist, (2) evaluation of psychotropic medications, (3) wheelchair repair, and (4) local environmental modifications, resulted in a reduced percentage of

individuals with two or more falls during 12 months of follow-up from 55% in the control group to 44% in the intervention group (Cumming, 2002).

- One review articles noted that home-based fall prevention programs have high participation rates in older populations (McInnes and Askie, 2004).
- However, social stigma attached to aging resulted in older adults being reluctant to use mobility aids and was sometimes a barrier to participation in prevention programs (McInnes and Askie, 2004). Reducing barriers to participation in prevention strategies in older adults is important in preventing falls. Barriers include having no prior history of falls, stigma of aging/frailty, inaccessible information, misconceptions about physical health, and lack of self-efficacy.
- Participation in prevention programs and education can be encouraged by promoting the social value of these programs, advocating their role in fostering independence in older people, making the programs accessible to elderly populations, providing timely referrals, and encouraging patient self-efficacy in fall prevention (McInnes and Askie, 2004).
- Injuries from falls may be prevented. Hip protectors in care homes exhibited a relative risk rate for hip fractures of 0.67 (0.46 to 0.98), although there was no significant effect on the number of falls (Oliver, 2007).

#### *Other Injuries*

- One review examined prevention of injury in people with intellectual disabilities. Effective strategies included: education on fire safety and first aid; improved home content design (smoke detectors, swimming pool fences, safety glass, padding on corners of hard-edged furniture, soft floor coverings, no bunk beds, child-resistant containers for household poisons and pharmaceuticals); information, education, and support for parents, schools, and disability services regarding specific home hazards; improvements in fitness and coordination; specific training for primary care physicians in providing injury prevention counseling to individuals with ID; and small group sessions teaching behavior modification techniques related to fall risk factors (Sherrard *et al.*, 2004).
- One review examined the prevention of poisoning in the general and pediatric population. To prevent accidental ingestion of ethylene glycol in all population age groups, the substance should be kept in its original container (specifically not transferring it to a food/beverage container), stored separately from food, and sealed with a child-proof cap. A bitter tasting substance can be added to avoid accidental ingestion (Leth and Gregersen, 2005).

#### **Factors impacting hospitalization for injury events among HCBS populations**

##### *Propensity to Present with Injury Events Among HCBS Populations*

- In comparison with the general population, persons with intellectual disabilities had a lower proportion of emergency room (ER) visits related to injury (26.5% vs. 30.4%) and were less likely to have multiple ER visits for injuries (Odds Ratio = 0.26, 95% CI 0.10-0.69) (Wang *et al.*, 2002).
- When persons with ID were admitted to the hospital for injury, the causes were less likely to be a motor vehicle crash (Odds Ratio = 0.30, 95% CI 0.15-0.62) but more likely to be a fall (Odds Ratio = 1.76, 95% CI 1.19-2.60). In the ER setting, persons with ID were more likely to be seen for poisoning (Odds Ratio = 6.05, 95% CI 2.97-12.32) and falls (Odds Ratio = 1.69, 95% CI 1.24-2.32). (Wang *et al.*, 2002).

##### *Frequency of Admission for Injury Events in HCBS Populations*

- In South Carolina in 1997, 199 people with intellectual disabilities were admitted to the hospital and an additional 194 visited an emergency room due to injury causes (Wang *et al.*, 2002).

*Differences in Threshold for Admission by HCBS Population, Practice Patterns or Socioeconomic factors*

- No related review articles.
- We looked specifically for studies addressing the impact of short stay units or emergency room practice patterns on injury admission rates, but found no relevant reviews.

**Documentation and coding of injury events**

*Physician Documentation*

- No related review articles.

*Sensitivity and Specificity of Diagnosis and External Cause of Injury Codes*

- Overall, 82.8% of injury claims for emergency department visits and hospital admissions had external cause of injury codes (E-codes), but only 59% of the claims for individuals with intellectual or developmental disabilities had E-codes (Wang *et al.*, 2002).

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## **Mental Illness and Potentially Preventable Behavioral Health Events**

For the purposes of this review, we sought information from published review articles on mental illness and behavioral health events for individuals receiving home care services and for two specific HCBS populations: (1) people with disabilities (intellectual, developmental, or physical) and (2) elderly individuals. We also included some information on serious and persistent mental illness in the general population, because some people with mental illness are themselves an HCBS sub-population. When available, we also include information on other potential HCBS populations.

### ***Prevalence of mental illness and behavioral health events in the HCBS populations***

- Few review articles provided information on prevalence of mental illness or behavioral health events in HCBS populations, other than in older adults.

### ***People with Intellectual, Developmental or Physical Disabilities***

#### **Serious and Persistent Mental Illness**

- The prevalence of affective disorders in people with intellectual or developmental disabilities (ID/DD) remains debatable; two recent reviews highlighted the wide range and limitations of published estimates (Janowsky, 2005; Kerker, 2004). Janowsky and coauthors found that some studies reported higher prevalence among individuals with ID/DD compared to the general population, while others reported similar or lower rates (Janowsky, 2005).

#### **Substance Abuse**

- Individuals with intellectual or developmental disabilities are reported to use and abuse alcohol at rates similar to the general population. However, reported use of illicit drugs is less frequent (Burgard, 2000).

### ***Elderly Individuals***

#### **Serious and Persistent Mental Illness**

- A review of large population surveys estimated the prevalence of any mood disorder in persons 55 years and older to be 7.2%, but reported that this estimate may be as low as 3.4% for clinically significant disease. This review further estimated the prevalence of clinically significant conditions by specific affect disorder: major depressive episode (2.7%), unipolar major depression (2.6%), dysthymia (1.6%), and bipolar disorder (0.1%) (Narrow, 2002). Other reviews reported estimates of the prevalence for bipolar disorder ranging as high as 0.4 to 0.5% in persons 65 years or older (Depp, 2004; Kilbourne, 2005). These reviews recommended caution when interpreting estimates of bipolar disorder in community-dwelling older individuals because a large-scale empirical evaluation that includes the community setting has not been done (Depp, 2004). Another review focusing specifically on mania in elderly individuals also recommended caution in interpreting prevalence estimates; that review reported a large discrepancy between prevalence of mania in psychiatric inpatients (20%), mania in long-term care (10%), and mania in the general population (1-2%) (McDonald, 2002).
- One review estimated the prevalence of comorbid bipolar and anxiety disorders among elderly individuals to be 92% in individuals who meet criteria for either bipolar or anxiety disorder (Sajatovic, 2006). Although evidence is limited, as many as 70% of older adults with bipolar disorder may have a co-existing personality disorder (Depp, 2004).
- In persons 65 years and older, one-year prevalence of affective disorders is approximately 0.6% for men compared to 1.5% for women (Jeste, 1999). Among older adults, the ratio of women to men with depression may be as high as 3.5-to-1 (Depp,

2004). One review estimated the one-year prevalence of bipolar disorder to be 0.1% for both men and women ages 65 years and older (Jeste, 1999).

- An older review estimated a significantly higher prevalence of depression (2.3% vs. 0.7%), anxiety disorders (2.2% vs. 0.4%) and dysthymia (3.9% vs. 1.7%) in elderly individuals who are unable to leave their home compared to elderly individuals who are capable of going out in the community (Bruce, 1992).
- In community-dwelling older adults, prevalence estimates for clinically significant depression (or chronic depression) ranged from 8 to 16%, with estimates as high as 25% when stratifying by race and estimates up to 35% in long-term care facilities (Beekman, 1999; Blazer, 2003; Palsson, 1997). Major clinical depression is thought to exist in 1% to 4% of older adults, although lower rates have been reported in older reviews (Blazer, 2003; Karel, 2000; Palsson, 1997). Minor depression or some symptoms of depression may be present in at least another 10% of older persons (Beekman, 1999).
- Major depression is estimated to be present in 10 to 12% of older adults admitted to the hospital for medical or surgical reasons, with another 23% showing some symptoms of depression in the inpatient setting; 5-10% of older adults presenting to primary care may experience major depression (Blazer, 2003). Psychotic manifestations of major depression may occur in 20 to 45% of these older adults when hospitalized (Blazer, 2003; Shanmugham, 2005), with an estimated 3.6% of community-dwelling older persons experiencing psychotic symptoms related to depression. An estimated 20% of depressed older persons are thought to have Alzheimer's disease, and these psychotic manifestations may be related to depression of Alzheimer's disease (Blazer, 2003).
- A review of large population surveys estimated the prevalence of any clinically significant anxiety disorder in persons 55 years and older to be 11.4%. However, 10% may be related to specific phobias (Narrow, 2002). Other authors reported that generalized anxiety disorder may be present in 1.9% - 7.3% of community-dwelling older individuals, with another 1.6% experiencing a combined depression-anxiety condition (Dada, 2001; Schoevers, 2003; Wetherell, 2005). Another review estimated that the prevalence of anxiety disorders ranged from 2 to 10% in older community-dwelling adults. This review also estimated that clinically significant levels of anxiety occur in 24% of the older community-dwelling population (Sajatovic, 2006). However, there may be conflicting evidence regarding the prevalence of generalized anxiety disorder in the elderly population, and there may be substantial under-estimates of anxiety in elderly populations (Dada, 2001; Wetherell, 2005).
- A review of large population surveys estimated that the prevalence of schizophrenia in persons 55 years and older was 0.6% overall, but only 0.4% of these individuals may experience clinically significant symptoms (Narrow, 2002).
- One review reported that five-year mortality may be as high as 50% in older individuals with bipolar disorder, compared to approximately 20% in those with depression (Depp, 2004).

#### Substance Abuse

- A review of large population surveys estimated the prevalence of substance use disorders in persons 55 years and older to be 2.8%. Most of those cases were thought to be due to alcoholism (Narrow, 2002).
- In a more recent survey, 7.2% of adults 65 years and older reported binge drinking, and another 1.8% reported heavy alcohol consumption (Bartels, 2005). Of those 50 years and older, 1.8% reported illicit drug use in the past month, with 1.1% using marijuana, 0.7% using prescription drugs for non-medical purposes, and 0.2% using cocaine

(Bartels, 2005). Other community surveys estimated problem drinking in older adults to range between 1% and 15%, with a prevalence of alcohol dependence of 1.8% among those aged 55-59, 1.5% in those aged 60-64, and 0.5% in those aged 65 or older (Bartels, 2005). Up to 11% of elderly persons may abuse prescription drugs (Culberson, 2008).

- These rates may be elevated in persons seeking medical attention. Among older adults seeking care in the primary care setting, between 5 and 15% may meet criteria for problem drinking. As many as 29 to 49% of older veterans may meet criteria for problem drinking and alcohol dependence (Bartels, 2005; Oslin, 2005).
- Among older individuals with bipolar disorder, prevalence estimates for any substance abuse disorder ranged from 13 to 30% (Sajatovic, 2006).

### Suicide and Self Harm

- One review of elderly individuals reported prevalence rates for completed suicides by age category and race. The prevalence of completed suicide among Caucasian women aged 65-69 years was less than 0.01% and this rate appeared to remain the same or decrease with increased age. The prevalence of completed suicides was extremely low among African American, Asian, and American Indian elderly women. The prevalence of completed suicide among Caucasian men aged 65-69 years was just over 0.02%, with a steady increase with increased age to just under 0.05% prevalence among Caucasian men aged 85 and over. The prevalence of completed suicide among African American men aged 65-69 was approximately 0.01%, with slight increases with increased age to just under 0.02%. (However, there was a decline in prevalence among African American men aged 85 and over). The prevalence of completed suicide among American Indian and Asian men was very low (Conwell, 2008).
- There may not be an effective surveillance method to accurately estimate suicide attempts or suicidal ideation in elderly individuals, but estimates from smaller surveys placed the number at lower than the general population (Conwell, 2008; Pearson, J. L., 2000). In an older VA study of individuals aged 60 years or older identified through the primary care setting, 7.3% reported thoughts of suicide.
- Persons aged 65 years and older account for 14% of completed suicides in the U.S. (Conwell, 2008). Elderly individuals complete suicide at a higher rate than the general population; the estimated ratio of attempted-to-completed suicides in older adults is much lower than in the general population (range 2/1 to 4/1 vs. 8/1 to 40/1, respectively). There is a greater chance that a suicide attempt by elderly individuals is likely to be fatal than in other populations (Conwell, 2008).
- Despite elevated rates of suicide among those with bipolar disorder and among older adults, rates of suicide appear to be lower in older adults with bipolar disorder than in each of these populations alone (Depp, 2004).

### *General Population*

#### Serious and Persistent Mental Illness

- Women may report depression symptoms more frequently and in greater quantity than men. Women with major depression may also be more likely to be prescribed medication, undergo psychotherapy, and be hospitalized than are men (Skultety, 2006).
- Individuals with bipolar disorder may be at higher risk for both relapse and rehospitalization (Baldwin, 2007).
- One review estimated the prevalence of psychosis in general community settings to be 0.2 to 4.7% and in long-term care settings to range from 10 to 63% (Hoeh, 2003).

***Clinical considerations for mental illness and behavioral health events in HCBS populations***

*People with Intellectual, Developmental or Physical Disabilities*

Serious and Persistent Mental Illness

- An older review of depression in intellectually disabled persons suggested that depression may be exhibited through unique behavior compared to the general population (e.g., aggression, self-injurious behavior, etc.) According to this review, there are no controlled studies focusing on the treatment of depression in individuals with intellectual disabilities (Davis, 1997).
- A more recent review commented on the dearth of evidence about effectiveness of community-based mental health treatment for individuals with intellectual disabilities (Hemmings, 2008).

Suicide and Self Harm

- Women with intellectual or developmental disabilities may exhibit suicidal behavior at levels similar to the general population of women; however, rates may be lower in men with ID/DD (Janowsky, 2005).
- Home-care patients receiving parenteral nutrition via a central venous catheter may be at increased risk for self-injurious behavior using the catheter (Stern, 2008).

*Elderly Individuals*

Serious and Persistent Mental Illness

- We identified a number of risk factors for depression in geriatric populations reported in systematic reviews. Risk factors identified by both univariate and multivariate analysis in more than one study included: disability, new medical illness, poor health status, previous incidence of depression, poor self-perceived health, and bereavement (Cole, M.G., 2005). Of the risk factors available for meta-analysis, those that emerged as significant included bereavement, sleep disturbance, disability, previous depression, and female gender (Cole, M.G., 2005; Jeste, 1999). Other possible risk factors included poor health status, cognitive impairment, living alone, and new medical illness (Cole, M.G., 2005). Severe alcohol and cigarette use may increase risk for depression in elderly individuals, while increased age may not be independently associated with risk for depression (Vink, 2008).
- Depression in community-dwelling older adults is commonly comorbid with physical and medical conditions. These conditions may also differ by race (Blazer, 2003).
- In older adults, depression is associated with experiencing disability (as measured in deficits of activities of daily living or instrumental activities of daily living) (correlation coefficients = 0.10-0.54, odds ratios = 1.9-4.9), and both conditions have been shown to be independent risk factors of the other. There may also be elevated rates of comorbid anxiety in these patients (Lenze, 2001).
- Estimated mean age-of-onset for any affective disorder in elderly individuals is 48 years (SD = 6.4, range 28-65 years), with the estimated age-of-onset for mania averaging 56.4 years of age (SD = 7.3, range 38-70 years). One review suggested a general trend toward a 10-year latency between the onset of an affective disorder and an individual's experience with mania (Depp, 2004).
- According to an older review, dysthymia may be associated with being limited to a chair or bed among elderly individuals who are unable to leave their home (Bruce, 1992).

- There are more women than men diagnosed with late-life bipolar disorder; however, this proportion is commensurate with the larger proportion of women in this population (Depp, 2004).
- The clinical course of bipolar disorder may change in late life. Researchers reported that manic episodes may be longer, of less intensity, or include increased hostility and irritability, and may be less amenable to pharmacologic therapy (Depp, 2004). Individuals with late-life onset of bipolar disorder may also experience an elevated rate of admission for mania compared to younger individuals; however, this rate may also be attributable to comorbid psychiatric conditions and neurologic disorders (Depp, 2004). Physicians treating manic or psychotic symptoms in elderly individuals may focus on physiological reasons as the precipitating factor rather than mental states, making diagnosis difficult (McDonald, 2002).
- Risk factors for late-life onset of bipolar disorder include comorbid neurological illness, cerebrovascular disease, and a family history of affective disorder (Charney, 2003). Older individuals with mania are significantly more likely to experience a neurological illness than those with depression (36% vs. 8%) (Depp, 2004).
- One review reported that 8.9% of older adults with bipolar disorder may misuse or abuse substances or alcohol, although another review reported a much higher range (19-25%) (Baldwin, 2007; Depp, 2004). Among older adults with bipolar disorder, 9.7% may experience comorbid anxiety and 4.5% may experience dementia (Baldwin, 2007). Although evidence is limited, as many as 70% of older adults with bipolar disorder may have a co-existing personality disorder (Depp, 2004).
- Patients with schizophrenia often show clinically significant reduction in symptoms with increased age, although symptoms may remain severe in old age (Van Citters, 2005). Late-life onset of schizophrenia happens in approximately 20% of cases (Van Citters, 2005).
- From a diagnostic standpoint, there may be substantial overlap between schizophrenia and depressive disorders in the elderly (Kasckow, 2008). As many as 40% of elderly persons with major depression may exhibit delusional or psychotic symptoms, and as many as two-thirds of elderly persons in a manic state of bipolar disorder may exhibit psychotic symptoms (Hoeh, 2003).
- Elderly individuals with Parkinson's disease may exhibit psychotic symptoms; however, these individuals experience a 15-fold increase in placement in a long-term care facility (Hoeh, 2003).
- Late-life onset of anxiety disorders is a rare event; in older patients, symptoms of anxiety are likely to have been encountered for a length of time (Dada, 2001; Sajatovic, 2006).
- Risk factors for anxiety in elderly individuals include cognitive impairment, high blood pressure, chronic disease, poor self-perceived health, and functional limitations (Vink, 2008). Symptoms of anxiety are correlated with disability (as measured through deficits in ADLs and IADLs) in elderly individuals, and anxiety may also be an independent predictor of disability when depressive symptoms are present (Lenze, 2001). As many as 65% of older adults with depression may exhibit symptoms of anxiety, with estimates of 23 to 47% having comorbid depression and anxiety disorders (Sajatovic, 2006).
- As many as 40% of elderly persons with major depression may exhibit delusional symptoms (Hoeh, 2003).

#### Substance Abuse

- Among the elderly population, substance abuse often stems from misuse of medications, including over- and under-use, or non-adherence to regimen, whereas in younger populations substance abuse is most often associated with use of illicit drugs. These

drug mis-use problems are complicated by the frequent use by older adults of both prescription and over-the-counter medications (Bartels, 2005).

- In persons 65 years and older, one-year prevalence of substance or alcohol abuse has been estimated at 2.75% to 3.1% for men compared to 0.5% for women; however, female gender has been associated with increased risk for misusing prescription medications (Bartels, 2005; Culberson, 2008; Jeste, 1999; Oslin, 2005). Elderly individuals abusing alcohol may also be at increased risk for abusing prescription medications (Culberson, 2008).
- Risk factors for substance abuse among the elderly population include loneliness, decreased mobility or ambulation, impaired sensory capabilities, chronic pain, poor physical health, and poor economic and social support (Bartels, 2005).
- As many as 20% of older adults with depression may abuse alcohol, and as many as 50% of older adults with a history of alcohol abuse may have depressive symptoms (Bartels, 2005).
- In older adults with bipolar disorder, estimates for any substance abuse disorder range from 13 to 30% (Sajatovic, 2006).

### Suicide and Self Harm

- Elderly individuals complete suicide at a higher rate than the general population; the ratio of attempted-to-completed suicides in older adults is much lower than in the general population (2/1 to 4/1 vs. 8/1 to 40/1, respectively). There is a greater chance that a suicide attempt by an elderly individual is likely to be fatal than for other populations (Conwell, 2008). This may also be due to the fact that many elderly persons are more frail, and self harm may have a more severe effect on them (Conwell, 2008).
- Individuals aged 65 years and older may be more likely to attempt suicide by firearm than the general population (72% vs. 52%) (Conwell, 2008).
- Male gender and older age are both associated with suicide completion; however, rates of attempts remain lower among elderly individuals than in the general population (Conwell, 2008). Rates of completed suicide may be 4 to 6 times higher for elderly Caucasian men compared to the general population (Bartels, 2005; Charney, 2003; Conwell, 2008; Pearson, J. L., 2000). One review reported that up to 75% of older men who attempted suicide had never made a prior attempt (Conwell, 2008).
- Risk factors for elder suicide include medical illness and functional disability; however, these risk factors may be mediated by the presence of depression (Bartels, 2005; Harman, 2001a). One review reported estimates of the presence of comorbid mental illness in elderly individuals, as identified through psychological autopsy following completed suicides: affective disorders (most major or clinically significant) were present in 54 to 87% of cases, while the presence of substance abuse disorders varied widely (3 to 46% of cases) (Conwell, 2008). Schizophrenia, delusional disorder, and anxiety played a very small role in these cases, but psychological disturbances were involved in an estimated 90 to 95% of suicides (Conwell, 2008; Pearson, J. L., 2000).
- Although personality traits may be associated with risk for attempted suicide in older individuals, personality disorders have not been associated with attempted suicide in this population (Conwell, 2008).
- Indirect Life-Threatening Behavior (ILTB) is also of concern among elderly individuals. These behaviors include refusing food, water, or medications (Pearson, J. L., 2000).

### *General Population*

#### Serious and Persistent Mental Illness

- Using 2003 VA administrative data to identify individuals with no record of previous home-care use (N=4,411,677), 24.2% of inpatients were discharged with a mental health diagnosis, of whom 1.5% used home-based primary care services within 3 years. Among all new home-care recipients, 40% had a mental illness diagnosis. Among all individuals included in the study, those with dementia were most likely to use home-care, followed by those with non-schizophrenia psychosis, miscellaneous affective disorders, and schizophrenia (Miller, 2007).
- One review suggested that gender may affect the age of onset for mania. Age of onset for women exhibited a bimodal distribution with higher risk associated during the third and fifth decades of life, whereas men may experience increased likelihood as age increases (McDonald, 2002).
- Presentations for anxiety may include a number physiological (e.g., frequent urination) and behavioral (e.g., withdrawal from prescription or psychotropic substances) symptoms (Dada, 2001).
- Delirium not present on admission may become apparent after admission in 5 to 30% of hospitalizations (Cole, Martin G., 2004).

#### Substance Abuse

- Withdrawal symptoms may increase the severity of presentation during an inpatient visit as hospital staff may not be aware of a current substance abuse/alcohol dependency in the individual (Oslin, 2005).
- Dual diagnosis of multiple psychiatric illnesses likely increases the risk for substance abuse, and complicates presentation and treatment of substance abuse. Of particular concern are depression, anxiety disorders, and cognitive impairment.(Bartels, 2005)

#### Suicide and Self Harm

- Risk factors for suicide include personal and family history of mood or anxiety disorder, family history of suicide, loneliness, hopelessness, access to handguns, and insufficient social support systems (Harman, 2001a). Access to firearms, and in particular handguns, is an independent risk factor for suicide in men (Conwell, 2008).
- In individuals with schizophrenia, up to 50% of suicidal intent appears in those with depressive symptoms (Kasckow, 2008).

#### ***Evidence of poor clinical or self care related to mental illness or behavioral health events in HCBS populations***

Clinical care includes coordination, access, education, pharmaceuticals, and tracking/monitoring. Self care includes factors such as adherence to clinical recommendations, diet, and smoking.

#### *People with Intellectual, Developmental or Physical Disabilities*

- No relevant information found.

#### *Elderly Individuals*

##### Serious and Persistent Mental Illness

- Although debatable whether attributable to quality of care, late-life depression and manic episodes often occur within the context of using medications to treat chronic illnesses (Charney, 2003).
- Older adults may be less likely to receive a recommended mood stabilizer as a first-line treatment for bipolar disorder and may be less likely to receive follow-up outpatient care

within 90 days compared to younger individuals with bipolar disorder, despite controlling for patient factors such as comorbidities (Kilbourne, 2005).

- One review reported that 11 to 23% of elderly individuals with bipolar disorder who receive lithium experience acute lithium toxicity (Sajatovic, 2005).
- A number of issues impact adherence to medication recommendations for depression in elderly individuals, including difficulty in noticeably reducing symptoms and presence of side-effects (Charney, 2003; Hayes, 2004; Karel, 2000; Williams, 2000; Wolf, 2008). Elderly individuals with comorbid medical illness may fail to adhere to treatment for depression up to 3 times as often as non-depressed elderly individuals (Hayes, 2004). Older adults with comorbid depression and anxiety are more likely to discontinue their medication than those only experiencing depression (Sajatovic, 2006).
- As many as 70 to 80% of elderly persons with psychotic symptoms may only partially comply with their medication regimens (Alexopoulos, 2004). An estimated 50% of elderly individuals with bipolar disorder discontinue their medication (Charney, 2003).

#### Substance Abuse

- Older adults with a dual diagnosis of mental illness and substance abuse are at higher risk for poor health outcomes; however, their pattern of healthcare service use tends to rely heavily on outpatient care rather than inpatient care, compared to individuals with psychiatric illness alone. Problem drinking or substance abuse may be under-recognized in primary care (Bartels, 2005).
- Substance abusers have an increased risk for medication interactions; older adults who abuse substances are at especially high risk due to the increased number of medications typically used by older populations. Despite recommendations to refrain from alcohol when taking certain medications, alcohol abusers are at heightened risk when concurrently taking benzodiazepines, barbiturates, and antidepressants (Bartels, 2005).

#### Suicide and Self Harm

- From a public health perspective, suicide has been considered inadequately treated depression (Pearson, J.L., 2001). In one review, the authors asserted that there is a dearth of information available for effective interventions in the prevention of suicide in elderly individuals, and the focus for treatment is therefore on comorbid depression (Pearson, J. L., 2000).

#### *General Population*

##### Serious and Persistent Mental Illness

- Up to 20% of individuals with depression may be inadequately treated (range 11-20%). Treatment failure for depression may range from 40 to 60%, and many more patients may simply be inadequately treated for depression (Masand, 2003).
- One review reported that lack of patient education from providers is associated with patients who discontinue medication for depression without physician consultation, although patient adherence to clinical recommendations also plays a role (Masand, 2003). Approximately 28% of people being treated for depression stop taking their medication within 1 month, and 44 to 54% discontinue depression medications (tricyclics and SSRIs) within 3 months of receiving the prescription (Masand, 2003).
- Some evidence suggests that individuals with mental illness are more compliant with treatment when offered their preferred mode of treatment (psychotherapy vs. pharmacotherapy or both) (Skultety, 2006; Wolf, 2008).

### *Other Relevant Populations*

- Using California Medicaid data, one study found that 37% of observed acute care inpatient encounters occurred during a gap in medication availability. Controlling for patient characteristics, the authors reported that between 9.5% and 12.3% of these admissions were attributable to gaps in medication availability (Marcus, 2008). This study was replicated using California Medicaid data from more recent years, which revealed that gaps in medication availability, medication consistency and persistence, and medication progression were significantly correlated with risk for hospitalization (Weiden, 2004).

### ***Factors impacting hospitalization for behavioral health exacerbations in HCBS populations***

#### Differences in frequency, presentation, and detection of behavioral health exacerbations

##### *Individuals with Intellectual, Developmental or Physical Disabilities*

- In a review of rapid-cycling bipolar disorder in persons with intellectual disability, those with severe disability have been observed to average 24.5 episodes per year (95% CI, 13.96-35.24) (Vanstraelen, 1999).
- A number of instruments have been validated for the detection of mental health issues specifically for the ID/DD population, and methods for the identification of “atypical” symptoms of depression in severely intellectually disabled adults have been identified (Perez-Achiaga, 2009; Ross, 2003).

##### *Elderly Individuals*

##### **Serious and Persistent Mental Illness**

- A number of authors reported a 45 to 48% recurrence of depression in older adults (Blazer, 2003). Rates of readmission (3 -7 years) may be similar for both major depression and bipolar disorder in older individuals (30-50%) (Depp, 2004).
- At 1 year, 12% of community-dwelling older adults with depression may recover and maintain wellness, and up to 31% may experience recovery without relapse at 6 years. One meta-analysis estimated that in community-dwelling elderly individuals with major depression or clinically significant depressive symptoms, 33% recovered, 33% remained depressed, and 21% died within 2 years (Cole, M. G., 1999). Other authors reported an overall recovery rate as high as 80% in elderly individuals without comorbid medical conditions or dementia (Blazer, 2003).
- On average, older individuals with bipolar disorder have been observed to be hospitalized in a psychiatric facility 4 times within a 10-year period (Depp, 2004).
- Among individuals with Alzheimer’s disease, estimates ranged widely for the percent experiencing a psychotic episode (12% to 74%), a delusional episode (9% to 63%), hallucinations (4% to 41%), or other psychotic symptoms (4% to 39%) at some point during the course of their disease (Ropacki, 2005). Ropacki et al. reported that the incidence of these episodes tended to increase for the first 3 years following initial diagnosis (mean age of disease onset = 70.1 years), but incidence typically plateaued after the 3-year mark (Ropacki, 2005).
- One review suggested that current nursing guidelines for in-home detection of depression in elderly individuals focus only on depressed mood, not anhedonia (Suter, 2008).
- Although older individuals in general may exhibit a difference in their propensity to present for depression, their lowered mood is often attributed to social, personal, or

medical circumstances by healthcare professionals (Baldwin, 2007; Blazer, 2003; Cole, M. G., 2006; Frederick, 2007; Suter, 2008). Furthermore, older individuals may also discuss depressive symptoms in terms of their ailments (Conwell, 2008; Harman, 2001b).

- Primary care physicians may under-diagnose depression in elderly individuals despite evidence that suggests that older adults are more likely to present to a primary care physician than to a mental health provider for psychiatric concerns (Harman, 2001b; Jeste, 1999). In one study, after controlling for symptoms reported during the visit, people over 65 years of age were 56% less likely to receive a depression diagnosis compared to younger individuals (Harman, 2001b). Up to half of elderly individuals with clinically significant symptoms of a mood disorder may not receive treatment from a primary care setting (Conwell, 2008). Anxiety disorders may also be under-diagnosed in elderly individuals in primary care settings (Vink, 2008).
- Manic or psychotic symptoms in older adults may cause physicians to focus on physiological reasons as the precipitating factor rather than mental states, making accurate diagnosis difficult in some individuals with bipolar disorder (McDonald, 2002). Similarly, the detection of anxiety in elderly individuals is often complicated by patient somatization of complaints rather than expressing a complaint as anxious in nature (Vink, 2008; Wetherell, 2005).
- Older adults may be substantially less likely to visit a mental health provider for symptoms of anxiety compared to affective disorders (17% vs. 55%, respectively) (Vink, 2008).
- Despite a low estimated prevalence in late-life, bipolar disorder may account for 8-10% of psychiatric admissions in older individuals (Depp, 2004).

#### Substance Abuse

- Race and ethnicity may dramatically impact the propensity of elderly individuals to present for substance abuse (Bartels, 2005).
- Older adults in general may be less likely to seek help for substance abuse problems than the general population (Bartels, 2005).

#### Suicide and Self Harm

- Community-based outreach has been shown to be a protective factor against suicide in isolated older adults. In this model, community-based non-healthcare workers such as utility workers or repair workers who observe worrying behavior or symptoms during their contact with elderly individuals have referral information ready (Bartels, 2005; Pearson, J. L., 2000; Salvatore, 2000).
- Older adults may be less likely to admit suicidal ideation to a caretaker or provider than younger individuals (Conwell, 2008).
- Many elderly individuals who complete suicide visit their primary care physician within one month prior to the suicide attempt, and many of these cases of suicidal ideation are not recognized by physicians (Harman, 2001b).

#### *General Population*

##### Serious and Persistent Mental Illness

- Although female gender has been associated with high rates of depression (Cole, M.G., 2005), men may present differently or not at all if their symptoms of depression are not in line with cultural stereotypes or personal beliefs held by the individual (Baldwin, 2007). One study, however, reported that even after controlling for reported depressive

symptoms, women may be more likely to receive a depression diagnosis than men in primary care settings (Harman, 2001b).

#### Frequency of admission

- Depressive symptoms and antidepressant therapy in community-dwelling older adults may not be related to differences in inpatient utilization, but may be related to increases in outpatient encounters and charges to outpatient organizations (Blazer, 2003). An older review suggested that these patients are heavier users of healthcare resources in all settings (Lebowitz, 1997).

#### Differences in threshold for admission by HCBS population, practice patterns or socioeconomic factors

- No related review articles.

#### Other factors impacting hospitalization rates

##### Local Laws

- No related review articles

##### Local Availability of Psychiatric Services and Practice Patterns for Admission

- Approximately 23% of Medicare expenditures for substance abuse covered inpatient services compared to 50% covering outpatient services (Bartels, 2005).

##### Poor Clinical Care

- No related review articles.

##### Poor Self Care

- No related review articles.

### ***Documentation and coding of mental illness and behavioral health events***

#### *Physician Documentation*

- No related review articles.

#### *Sensitivity and Specificity of ICD-9 Diagnosis Codes*

- One study assessed algorithms using ICD-9 codes and pharmaceutical treatment data to identify individuals with depression one year after experiencing a stroke admission at a VA hospital (N=185) (Damush, 2008). They assessed the following ICD-9 codes associated with depression:
  - 296.2x (single episode or unspecified major depressive disorders)
  - 296.3x (recurrent major depressive disorders)
  - 311.xx (depressive disorder, not elsewhere classified)
  - 300.4 (reactive depression)
  - 309.0 (depressive reaction, acute)
  - 309.1 (depressive reaction, prolonged)
  - 331.9 (cerebral depression)
  - 437.8 (cerebrovascular depression)

The authors determined that the best algorithm was presence of one depression code or an approved dose of antidepressant (Sensitivity = 62%, Specificity = 88.9%, PPV = 67.4%, AUC = 0.75). When using only ICD-9 codes (primary or secondary diagnosis; inpatient and outpatient), sensitivity was lower, as was area under the ROC curve. However, specificity and positive predictive value were slightly higher (Sensitivity = 44%,

Specificity = 94.8%, PPV = 75.9%, AUC = 0.69). The authors recommend using pharmacy data.

- Spettel et al. (2003) assessed two algorithms to identify patients with depression in a large managed care organization database (N=465) (Spettel, 2003).
  - Algorithm 1: required diagnosis codes (296.2–296.36; 300.4; 311) or pharmacy data on two separate “events” and these could come from the same category (for example, could be two fills for separate prescriptions for depression)
  - Algorithm 2: required that at least one of the events mentioned in Algorithm 1 be an encounter leading to diagnosis of depression.

Study results revealed that 121/465 records contained a diagnosis of depression, of which 9% met DSM-IV criteria through documentation in the record. Of the 234 cases identified by Algorithm 1, 54% had no diagnosis of depression in their administrative data and 84% of false-positives had antidepressant data (Sensitivity = 95%, Specificity = 65%; PPV = 49%). Use of antidepressants by false-positives in Algorithm 2 was much lower (53%), although sensitivity was also lower (Sensitivity = 52%, Specificity = 88%; PPV = 61%). Overall, the authors cautioned use of administrative data to identify patients with depression.

- Looking at ICD-9 codes (296.0x, 296.1x, and 296.4x to 296.8x) in a Veteran’s Health Administration database for bipolar disorder (Pennsylvania, 1999-2000), 31% of those with bipolar disorder also received a concurrent schizophrenia diagnosis and 54% received a concurrent major depression diagnosis within the same fiscal year. Older African Americans with bipolar disorder were the most likely subgroup to receive a concurrent diagnosis for schizophrenia (Kilbourne, 2005); (Kilbourne, 2004). Schizophrenia is considered a clinically distinct condition from bipolar disorder and these data may warrant investigation into the overlap between coding for these conditions in administrative data (Kilbourne, 2005). Also worthy of mention are concurrent ICD-9 diagnoses within the same fiscal year in individuals with bipolar disorder in this database: alcohol use disorder (30%), drug use disorder (14%), post-traumatic stress disorder (14%), other anxiety disorder (11%) (Kilbourne, 2004).

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## Unmet Needs Literature

Several experts who viewed an earlier draft of this review recommended examining evidence related to adverse consequences of unmet needs for help with activities of daily living (ADL) or instrumental activities of daily living (IADL). Unlike the other sections of this review, our brief review of the unmet needs literature was not focused on particular candidate indicators or HCBS populations. Rather, we looked for information that would inform development or interpretation of the HCBS QIs, such as clinical outcomes or healthcare utilization associated with unmet needs.

### ***Consequences of unmet need for assistance with Activities of Daily Living (ADL)***

#### *Healthcare Utilization*

- In a survey of 632 adults with disabilities in Springfield, MA, respondents with unmet needs for assistance with ADLs had significantly higher healthcare utilization in the year prior to the survey compared to those whose ADL needs were met, as measured by average number of hospitalizations (1.1 for unmet needs group, vs 0.5 for met needs), emergency department visits (1.5 vs 0.7), and outpatient visits (16.7 vs 10.1). There were no statistically significant differences in healthcare utilization between those with and without unmet needs for instrumental activities of daily living (IADLs), although individuals with unmet transportation needs had significantly more ED and outpatient visits (Allen and Mor, 1997).
- In a sample of 2,943 frail older people enrolled in a comprehensive program to provide medical and support services to community-dwelling elderly individuals in need of ADL assistance (PACE program), rates of hospital admission for acute conditions prior to program enrollment were significantly higher for those with unmet needs (56%) compared to those with met needs (48%). Among participants who had unmet needs prior to enrollment in PACE, the rate of acute hospitalization declined between 7 and 12 weeks after program enrollment (6% hospitalized), compared to the hospitalization rate during the first 6 weeks of the program (12%). Even when adjusting for program site and demographic, socioeconomic, and health factors, individuals with unmet needs prior to enrollment were more likely than those with met needs to be hospitalized during the 6 months prior to enrollment (OR 1.26, 95% CI 1.01-1.57) and during the first 6 weeks of program enrollment (OR 1.44, 95% CI 1.00-2.08), but not 7 to 12 weeks after enrollment (OR 0.79, 95% CI 0.50-1.25). The delayed improvement in hospitalization rates after program enrollment was expected, as it was assumed that the health consequences of living with unmet needs would not resolve immediately after needs were met (Sands, 2006).
- There was no significant difference in the number of self-reported hospitalizations in the year preceding a survey of 1502 emergency department patients in Tennessee with and without unmet substance abuse treatment needs. Those with unmet needs did report greater numbers of emergency department and physician office visits. Compared to those without treatment needs, respondents with unmet treatment needs were 1.5 times as likely to have visited an emergency department (ED) in the previous year and 1.8 times as likely to be admitted as a result of their current ED visit (Rockett, 2005).
- In a study of 1,772 elderly individuals from a single city in Japan, individuals having difficulty with medication management but who lacked medication assistance were more likely to be hospitalized during the 3 year study period than those who did not need medication assistance (HR 1.32 95% CI 1.01-1.73), even when adjusting for potential confounders (Kuzuya, 2008).
- In a study of 1,354 elderly adults enrolled in one of Indiana's Aged and Disabled Medicaid waivers, all three types of HCBS waiver services evaluated were associated

with lower hospitalization compared to those who did not receive the waiver service. Receipt of home-delivered meals was associated with a 10% lower hazard of hospitalization compared to those who did not receive home-delivered meals. This effect did not change over time. Receipt of attendant care and homemaking services were both also associated with lower hazard of hospitalization, compared to those who did not receive such services. However, this effect diminished over time and became non-significant after approximately 1 year of program enrollment. In addition, individuals receiving a greater volume of services had a lower hazard of hospital admission compared to those who received fewer services. In the first month after enrollment, receipt of attendant care services was associated with a 54% lower hazard of hospital admission for those receiving 5 hours per month of services, whereas those receiving 25 hours per month of services had a 75% lower hazard of hospital admission. Likewise, in the first month after enrollment, receipt of homemaking services was associated with between a 48% (2 hours/month) and 68% (6 hours/month) lower hazard of hospital admission (Xu, 2010).

#### *Other Adverse Consequences*

- In a sample of 5,831 recipients of dementia care and their caregivers, care recipients with unmet needs on 2 or more ADLs were more likely to be placed in a nursing home (OR 1.77,  $p < 0.001$ ) and to die (OR 1.37,  $p = 0.01$ ) compared to those with no unmet needs (Gaugler, 2005).
- In a survey of 632 adults with disabilities in Springfield, MA, respondents reporting unmet needs were more likely to experience a negative consequence as a result of that need for 13 of 16 consequences examined. Examples of such consequences include inability to eat, falling, soiling oneself and missing doctor's appointments (Allen and Mor, 1997).
- In a nationally representative sample of 9,646 community-dwelling adults who need help with at least one ADL or IADL (instrumental activity of daily living), people with unmet needs for assistance reported significantly higher rates of adverse consequences than those with met needs on 29 of 34 consequences assessed. These included consequences related to indicator events and conditions such as unintentional weight loss (14.1% vs 32% met vs unmet needs groups), dehydration (4.6% vs 11.8%), inability to follow special diet (0.7 to 1.4% vs 20.9 to 12.7% depending on reason attributed to consequence) and missed doctor's appointment (2.8% vs 12.7%). People with unmet needs also experienced significantly higher rates of falls (45.8% vs 55.1% met vs unmet needs), including multiple falls (71.6% vs 82.0%) and injurious falls, (55.7% vs 68.8%) and pressure ulcers (6.0% vs 9.1%). This study also showed that when assistance needs were met, people living alone had similar rates of adverse consequences as those living with others, suggesting that it may not be necessary to risk adjust for living situation when comparing indicator rates (LaPlante, 2004).
- A 1999 survey of elderly community-dwelling dual eligibles revealed that 58% had unmet needs for assistance with ADLs (Komisar, 2005). More than half of these individuals experienced at least one of 5 adverse consequences associated with unmet need (not able to bathe, not able to dress, soiled self, went hungry or fell). Falls were much more common among those with unmet needs (48%) compared to those with met needs (28%).

#### ***Services and program features associated with QI outcomes***

- Controlling for baseline characteristics, 228 adults with mental illness in New Jersey enrolled in the Cash and Counseling Demonstration and Evaluation (CCDE) program

were not significantly more likely than those receiving traditional agency-directed services to experience falls, urinary tract infection, pressure ulcers, shortness of breath or hospitalizations during the month prior to program evaluation. Those in the self-directed CCDE program were 41% less likely to experience a respiratory infection (Shen, 2008a).

- In multivariate analyses, there were no significant differences in odds of adverse health consequences, including falls and injuries while receiving care, between elderly Medicaid beneficiaries managing self-directed support services (under the CCDE program) and those receiving agency-directed services (Shen, 2008b). Beneficiaries with mental illness fared just as well under the CCDE (Cash and Counseling Demonstration and Evaluation) program as those without mental illness: there was no interaction between participation in the self-directed care program and mental illness.
- In a sample of 526 Medicaid-eligible patients with HIV/AIDS attending one of 6 infectious disease clinics in the southeastern U.S., presence of at least one unmet need for support services was associated with not taking HIV medication ( $p=0.007$ ) and poor medication adherence ( $p=0.013$ ). Unmet need for support group services and healthcare benefits (such as assistance buying prescriptions or help obtaining social security or Medicaid benefits) were associated with not taking medication. Unmet need for mental health counseling was associated with poor medication adherence. Use of illicit drugs within 6 months of the survey was also associated with poor adherence (Reif, 2006).

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## Unmet Needs

- Shen C, Smyer MA, Mahoney KJ, *et al.* (2008b). "Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling program." *Gerontologist* 48(1): 93-104.
- Xu H, Weiner M, Sudeshna P, *et al.* (2010). "Volume of Home- and Community-Based Medical Waiver Services and Risk of Hospital Admissions." *Journal of the American Geriatrics Society* 58: 109-115.

## Appendix: Key Search Terms

### Key Populations

"Home Care Services"[Mesh]

("Community Health Services"[MeSH] OR "Home Care Services"[MeSH] OR "Intermediate Care Facilities"[MeSH])

("Medicaid" or " Medical Assistance, Title 19" or "waiver 1915" or "1915(a)" or "1915(b)" or "1915(c)" or "1915a" or "1915b" or "1915c" or "1915 (a)" or "1915 (b)" or "1915 (c)" or "1915 a" or "1915 b" or "1915 c")

("Long Term Care" or "Home Care Services" or "Home Care Services, Hospital-Based" or "Home Care Agencies" or "Foster Home Care" or "Home Health Aid\*" or "Home Nurs\*" or "Assist\* Living" or "Assist\* Living Facilit\*" or "Nurs\* Home\*" or "Home Based Care" or "Home Care Based Services" or "In House Care" or "House Nurs\*")

"Developmental Disabilities"[Mesh]

"Mental Retardation"[Mesh]

("Mental\* Disab\*" or "Mental\* Retard\*" or "Develop\* Disab\*" or "Disab\* Develop\*" or "Devop\* Delay\*" or "Intellectual\* Disab\*")

"Disabled Persons"[Mesh]

"Frail Elderly"[Mesh]

"Aged"[Mesh]

"Aged, 80 and over"[Mesh]

"Dementia"

### Quality Indicator Health Events

("hospitalization"[MeSH] OR "emergency medical services"[MeSH])

#### **Measure Set 1**

Search strategies developed for the set of AHRQ PQI and the Pressure Ulcer PSI were limited to HCBS populations using key words listed above. Details of the AHRQ PQI and PSI search strategies are available upon request. For more information, contact Sheryl Davies at [smdavies@stanford.edu](mailto:smdavies@stanford.edu).

#### **Measure Set 2**

##### ***Injuries Inflicted by Others***

"abuse"

"elder neglect" OR "elder abuse" OR "aged abuse" NOT "self-neglect"

##### ***Errors of Medication Administration***

("Medicat\* Error\*" OR "Prescri\* Error\*" OR "Medicat\* Admin\* Error\*" OR "Prescri\* Admin \*Error\*")

"Failure to administer life-saving", "Failure to prevent medication interaction", "Failure to prevent prescription interaction"

"Adverse Drug Event"

##### ***Accidental Injuries Potentially Due to Neglect***

"wounds and injuries"[MeSH] OR "accidental injury"[MeSH]

"accidental falls"

"fire or burn injury" OR "electric shock" OR "smoke inhalation" OR "electric burn"

"drowning" OR "near drowning"

"wounds, gunshot" OR "firearms"

"poisoning" OR "accidental poisoning" OR "toxins, biological/poisoning" OR ("poisoning" NOT "drug or medicinal or alcohol") OR "carbon monoxide poisoning"

"heat exposure" OR "cold exposure"

##### ***Mental Illness and Substance Abuse***

## Appendix

("Depression"[Mesh] OR "Depressive Disorder"[Mesh] OR "Depressive Disorder, Major"[Mesh]);  
"Depression, Postpartum"[Mesh]  
("Affect\* Disorder\*" or "Affect\* Symptom\*" or "Mood Disorder\*" or "Depress\*" or "Cyclothym\*" or  
"antidepress\*")  
"Bipolar Disorder"[Mesh]  
"Schizophrenia"[Mesh]  
("Schizophren\*" or "Psychosis" or "Psychotic" or "Antipsychot\*" or "Dement\*" or "Delir\*" or "Amnes\*" or  
"fugue" or "Alzheimer\*" or "Memory Disorder" or "Memory Loss")  
"Anxiety Disorders"[Mesh] OR "acute stress" OR "acute anxiety"  
("anxi\*" or "anxiety disorder\*" or "anti-anxi\*" or "separat\*" or "anxi\* agent\*" or "anti anx\* agent" or "stress\*" or  
"post traumat\*" or "stress disorder\*" or "acute stress\*" or "stress\* acute" or "chronic stress\*" or "stress\*  
chronic")  
"Personality Disorders"[Mesh]  
"Psychotic Disorders"[Mesh]  
  
"Substance-Related Disorders"[Mesh]  
"Alcoholism"[Mesh]  
("Substance Related Disorder\*" or "Substance Abus\*" or "Substance Depend\*" or "Drug Abus\*" or "Drug  
Depend\*" or "Alcoholi" or "Alcohol\* Depend\*" or "Prescrip\* Abus\*" or "Medicat\* Abus\*" or "Illicit Drug  
Use")

### ***Suicide and Self harm***

("Suicide"[Mesh] OR "Suicide, Attempted"[Mesh])  
("suicid\* attempt\* suicid\*" or "suicid\*, attempt\*" or "indirect life threatening behavior" or "ILTB" or "food  
refus\*" or "water refus\*" or "medication refus\*" or "refus\* food" or "refus\* water" or "refus\* medicat\*" or  
"self harm\*" or "refus\* treatment" or "treatment refus\*")

### **Unmet Needs**

Articles included in the brief review of unmet needs literature were identified in three ways:

- Recommendation of specific articles by experts in disability and unmet needs research.
- Pubmed search of key terms:
  - ("unmet need\*") AND ("disability\*")
  - ("unmet need\*") AND ("outcomes")
- Pubmed search of key authors (as recommended by experts):
  - Kaye, Stephen H.
  - Allen, Susan M.
  - Harrington, Charlene